PUBLIC INVOLVEMENT IN PRIMARY CARE: AN ANALYSIS OF POLICY IMPLEMENTATION

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ABSTRACT

Public involvement in primary care has gained increasing acceptance through a sustained position in government policy since New Labour began in 1997. When Primary Care Groups (PCGs) were introduced (Department of Health 1997), they were seen as vehicles for public involvement, reflecting devolution of power and local decision-making. During the process of this study (1999 – 2006) policy directives have highlighted a number of paradoxes, with the potential to impact on public involvement. Detailed development was left to local discretion, set against a national agenda that emphasised citizenship and consumerism. The purpose of this study was to explore, interpret and understand how public involvement policy was interpreted and implemented within the new organisational structures. The study was designed to address the research question 'How is public involvement defined and operationalised within PCGs`. Due to the pace of organisational change, the research expanded to track lay experiences within Primary Care Trusts (PCTs). The research methods included case study, national survey, telephone interviews and the development of a conceptual framework for public involvement in primary care.

From the analysis of the national survey and two in-depth case studies, the study provided a detailed profile of lay members across England. Issues regarding representativeness and the identification of a potentially discriminatory appointment system were raised. Despite inadequate training lay members were strongly represented in public involvement and health-related issues but less so in financial and operational areas. There were widespread difficulties with individual capacity and a minority of members identified themes relating to isolation, exploitation and lack of skills recognition.

There was little evidence of strategic and organisational development in implementing and responding to involvement initiatives. The majority of approaches to public involvement within this study focused on information exchange and therefore, were tokenistic in relation to power sharing. The impact of the national agenda was evident and the lack of specific central directives relating to involvement led it to remain a low priority. As the move to PCT status became central, public involvement was reclaimed as a management prerogative. The analysis showed that the concept of

citizenship, so central to Third Way politics was poignantly missing. The study reflected a focus on service users and the different roles of citizen and user were not clearly demarcated. The use of Foucault's concepts of governmentality and discipline provided an explanatory framework for elucidating the study's findings. The effects of governmentality embedded in policy directives and disciplinary mechanisms within NHS organisations were identified as crucial factors for the lack of significant progress of public involvement over the period of the research study.

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Introduction

This policy-based study sets out to explore public involvement in primary care organisations from the formation of Primary Care Groups (PCGs) in 1999 until the progression to Primary Care Trusts (PCTs) in 2001. Public involvement became an influential concept within health policy during the 1990s. It was seen as the vehicle to restore public confidence in the National Health Service (NHS) (Barnes 1999) and was an integral part of New Labour policy. Whilst enabling openness and transparency in public sector decision-making (Beresford and Croft 1993, New 1999), it is also seen as a way of decentralising such decision-making (Giddens 1998). Devolution of control to local areas was viewed as a way of establishing or restoring a sense of community and ownership. Part of this move to decentralisation and devolution was evident in the formation of PCGs in April 1999. PCGs were charged with health improvement, primary care development and the commissioning of services within their locality ('The new NHS, Modern and Dependable' Department of Health (DoH) 1997), with a visible remit for public involvement. Such involvement was seen as having the potential to deliver better health outcomes and more responsive services (Beresford and Croft 1993, McIver 1998, Barnes 1999). Furthermore, it was hoped that greater public involvement would lead to a clearer understanding of the workings of the NHS and more realistic expectations (Chambers 2000).

However, public involvement is difficult to conceptualise and is allied to multiple definitions. Its changing nature is dependent on why, when and where such involvement takes place (Gurney 1995). This fact is reflected in its diverse methodology. Involvement methods require skill and expertise but such skills were lacking within NHS organisational structures (Chambers 2000). Furthermore, initiatives required adequate resources and capacity building (Barnes 1999) and typically there were service constraints, particularly in relation to personnel, time and finance (Whitehead and Ray 1999, Chambers 2000). Davies (1999) highlighted the organisational tension between policy implementation and the needs of the public, short-term objectives often at odds with the time-consuming nature of genuine involvement. Difficulties were further compounded by a lack of formal evaluation of initiatives (Beresford and Croft 1993, McIver 1998). The greatest problems, however, were evident at an ideological level and related to aspects of power.

For public involvement to be truly effective, a shift of power away from health professionals was seen as a necessity (Chambers, 2000). However, the NHS reflected a public institution where democratic accountability had slowly been eroded (Harrison and Mort 1998). Emerging health policy would have to be played out in a professionally dominated arena, with vested interests and a reluctance to shake off paternalistic attitudes. Predominant professional views saw the public as apathetic and disinterested (Davis 1999), or lacking the competence to understand complex medical, scientific and managerial issues (Entwistle et al 1998). Those who did participate were labelled as unrepresentative or having hidden agendas. Public opinion revealed failing confidence in health services, with greater demands for information and rights, but with little related discussion of public responsibility.

In recognising the difficulties in defining public involvement it became crucial at the beginning of the development of this study to set the definitional parameters in which the research was to operate. The term public involvement is utilised throughout this study. It was the term most commonly utilised within health policy and concept-related texts within the lifespan of the thesis and had the definitional capacity to include both participation and consultation (Gurney 1995). The purpose of the study was to develop an understanding of how health policy was interpreted and implemented within new NHS organisational structures. The research question was stated as 'How is public involvement defined and operationalised within Primary Care Groups'. Specific research objectives were identified as: -

1. To provide a demographic profile of lay members serving as members on the governing boards of PCGs
2. To document and analyse the experiences of lay members on the governing boards of PCGs
3. To explore the developing role of the lay member
4. To explore the concept of public involvement utilising professional and lay perspectives
5. To identify and assess methods of public involvement initiated by PCG governing boards
6. To describe the development and implementation of the PCG public involvement strategy

This study makes a deliberate theoretical demarcation between public and patient involvement for two main reasons. Firstly, many texts and policy documents, although not all, make this differentiation (see Lenaghan 1997, Lomas 1997, Harrison and Mort 1998, McIver 1998, Sanderson 1999, DoH 2001a). Patients and the public were identified within such literature as having different roles, rights and responsibilities in relation to involvement (Lomas 1997). Lenaghan (1997) suggested that patients/users have a definite and personal interest in a specific service, whereas, the public or citizens had a widespread, long-lasting and general interest in health and health services. It is this broader capacity that was of interest to this study: -

'Service users and the public or citizens can be separated because a person can have an interest in public services as a tax payer, even though he or she may not currently use them' (McIver 1998:3)

Secondly, to encompass all aspects of involvement was an unrealistic remit for this study. Therefore, the important area of patient involvement was not addressed - Brearley (1990) and Crawford et al (2002) have extensively covered this area. McIver (1998) also identified the strong emphasis of patient rather than citizen involvement in previous NHS initiatives. This study's focus was an attempt to address some of this bias. However, a potential anomaly was the inclusion of patient participation groups (PPGs) within the study. As most people have a right to be registered with a general practitioner, in one respect we are all patients. Involvement within PPGs often includes a mixture of current and potential users and activities can involve both self and collective interest. It was in this latter capacity that members of PPGs were incorporated into this study and specifically relates to their participation in public involvement subcommittees.

The establishment of PCGs offered a unique research opportunity to study how public involvement was defined and operationalised within a totally new context. Only two clear and recognisable factors emerged from health policy, a layperson would be a member of the PCG governing Board and the new organisation would have to develop a public involvement strategy. The study of the lay member within this new context was crucial, most importantly because the lay member was linked to leading public involvement (NHS Confederation/The Institute of Health Services

Management (ISHM)/NHS Executive 1998). Beyond this suggestion the role of the lay member remained relatively unclear. Government documentation reflected limited credentials for participation, with no skills or expertise identified (HSC 139 1998). An investigation into the developing role of the lay member seemed pertinent at this time.

A predominant lay profile had already been established. Such people had specific characteristics and came from a narrow unrepresentative section of society. Concerns highlighted by many authors suggested such participants tended not to challenge the status quo, doing little to affect the inverse care law (Richardson 1989). However, the need to fill almost 500 lay positions within these new organisations presented an opportunity for widening participation. Therefore, the development of an up-to-date demographic national profile was seen as important. Lay involvement had the capacity to facilitate active citizenship and encourage personal development. However, lay members would also be operating within a professionally dominated board and literature identified concerns regarding potential isolation (Persuad 1999). It was clear that the research also needed to identify emergent roles and to capture aspects of their experiences.

The complexity and sheer number of methods of involvement available was evident (Barker et al 1999). Each places professionals and the public at different places on a continuum of power sharing. Historically, the NHS has utilised top-down initiatives and public involvement methods predominantly facilitated information exchange rather then citizen empowerment. However, health policy placed a stronger emphasis on co-operation and partnership (DoH 1997), with potential for a combined lay and multi-agency PCG board to attempt greater diversity in methodological approach. Cataloguing and assessing methods was to be an important aspect of the research, particularly in relation to the level of empowerment afforded to the public.

Health policy also identified that involvement should be systematic and on going but, historically, NHS organisations had fallen short of this requirement. Government policy also emphasised the need for feedback and the ability to demonstrate the effects of involvement. PCGs needed to develop an effective communication strategy as well as building organisational capacity with the ability to deal with the responses and recommendations related to involvement initiatives. Devolution had the potential

to localise decision-making and give some organisational flexibility in relation to public involvement. However, there was also the possibility to be restricted by health authority subcommittee status and central directives. The progression to PCT complicated issues further with the relatively short shelf life of the new organisations having the potential to impact on local involvement initiatives. Therefore, tracking the organisational development in relation to the public involvement strategy was essential to the study.

The concept of public involvement is not static and is often dependent on current political ideology with its chameleon-like nature emphasised by its changing terminology. With definitional difficulties at policy level, it was important to explore how public involvement was perceived and defined at PCG level. Part of the research, therefore, was to explore the perspectives of the key players within this new context. The main aspects of the study are reflected within the following chapter outlines of the thesis.

Chapter One charts the developing relationship between the NHS and public involvement from 1947 to 1996. The historical perspective sets public involvement within changing demographic, political, economic and socio-cultural contexts and shows how policymaking has shaped the concept over time. Such policymaking is seen often as reactive, occasionally divisive, placating public concern or attempting to rein in the medical profession rather than as a tool for empowerment. Analysis of the history of the NHS reveals medical dominance, a disempowered and fragmented voluntary sector and a continuing democratic deficit. However, despite commitment issues and the difficulty in gauging the impact of public involvement, the historical perspective identifies its continuing and growing emphasis within health policy.

As policymaking fails to clearly define public involvement, Chapter Two includes an analysis of the concepts of 'public' and 'involvement'. Public involvement must be played out on a strategic level and key elements relating to planning, implementation and evaluation are discussed. The chapter also identifies the central issue of power within public involvement, as power sharing and cultural change are linked to its success, and gives a brief exploration of theoretical interpretations of power. A stronger emphasis is placed on the work of Foucault as the related concepts of

governmentality, discipline and resistance are utilised as part of an explanatory framework within the study (see Chapter Five & Nine).

Chapter Three presents an evaluation of research, literature reviews and reports in relation to the effectiveness of public involvement. The chapter focuses on evidence predominantly from the past 20 years with a specific emphasis on primary care and citizen involvement initiatives within the United Kingdom, which reflected the focus of the research project. The chapter concludes that measuring the effectiveness of public involvement is as complex as the concept itself as the answer is dependent on the definition of success. Success, within this research project is linked to outcomes, particularly service development and the level of power sharing evident in public involvement initiatives.

Chapter Four explores the influence of Third Way politics and globalisation on the concept of public involvement within the health service. The emergence of PCG/Ts, unlike previous experiments in primary care, required compulsory professional and lay participation. The chapter maps the progression of PCGs towards Trust status amongst a backdrop of frantic government directives, rapid organisational change and escalating health service scandals. It explores the impact of these service scandals and subsequent reports on health policy and assesses the impact of new centrally generated involvement vehicles on the concept's future within the health service.

Chapter Five elaborates on the research design. The research question and the six main objectives are addressed using a multi method approach involving case study, national survey, telephone interviews and an explanatory conceptual framework. Each method represents a distinct phase of the research covering a data collection period over two years. Data analysis tools include statistical, category and discourse analysis and the use of a Foucauldian approach in relation to the explanatory framework. The chapter also includes a discussion on validity, reliability, generalisability, ethics and the role of the researcher and assesses the strengths and weaknesses within the study.

The results of the research study are organised into four further chapters within the thesis, each covering a data collection activity and analysis. National survey, case studies, telephone interviews and conceptual framework are presented separately and

form Chapters 6, 7, 8 and 9. Chapter 6 presents data analysis from a national survey of lay members (Phase Two) and relates specifically to role development and personal/occupational profiling. Though Phase Two of the research design it formed the first logical sequence of data analysis of the study. Chapter Seven presents data analysis from Phase One of the research project and focuses on two PCGs as part of a two-year case study. Chapter Eight presents data analysis from interviews with three distinct groups of lay members (Phase Three), which included non-executive directors and Chairs within PCTs (operational in April 2001). Furthermore, Chapters 6, 7 & 8 represent the exploratory phase of the research study. Chapter Nine represents the final explanatory phase (2004-2006). Utilising data from Phase 1, 2 and 3 the analysis focuses on issues of power and is presented utilising a Foucauldian approach.

The final chapter presents the discussion and conclusions from the research study and its contribution to the academic field. The main findings reflect an unchanging lay profile. The majority of lay members were linked to a role within public involvement and although receiving inadequate training, many found the experience enjoyable and rewarding. Some were to maintain their links with the health sector by developing new roles with Primary Care Trusts. Others, however, found the lay experience isolating and felt excluded, with skills and expertise left unacknowledged. Predominantly, methods of involvement focused on consultation and information exchange, with a continuing resistance to power sharing. Public involvement failed to develop strategically and systematically within the organisations researched. National targets and central directives superseded the devolution of power, advocated in recent health policy and public involvement was a casualty of this centralised control. Discussion focuses on future developments in primary care and the potential implications for public involvement. Again the chapter returns to the importance of cultural change and briefly reviews recent innovation in lay participation.

CHAPTER ONE

Public involvement and the NHS – historical perspective (1947 – 1996)

Introduction

Public involvement is a well-established principle (Richardson 1989) and is visible within many public and private arenas, evolving at local, national and global levels. Set within such diversity, this historical perspective focuses on the context of health, specifically exploring the NHS in England and its developing relationship with public involvement from its inception in 1947 up to 1996. Policymaking evolves within a number of important contexts – political, demographic, economic and socio-cultural (Lowe 1993) impinging on its creation and implementation. Such contexts provide an essential framework for examining health policy and its impact on public involvement. This perspective reflects the effect of factors such as economic crisis, public scandals, social unrest, political ideologies and medical dominance on the concept of involvement over a fifty-year period.

1.1 Pre-NHS Service Provision

Powell (1997) asserts that analysis of pre-NHS services is essential in understanding the development of the NHS as the original aims of a national health service were strongly linked to the intrinsic difficulties and limitations within the previous system. More pertinent to this review, analysis of pre-NHS services also identify the nature of public involvement, its changes and consistencies, through the transition into a national health service and beyond. The review produced a confused picture of healthcare pre-NHS, with limited, under funded, poorly organised, uncoordinated and unevenly distributed services, which involved multiple providers. Pre-NHS services were market and charity led, involving local authorities, charitable organisations and private general practice (Boaden et al 1982, Lupton et al 1998).

The voluntary sector had emerged during a period of philanthropic enthusiasm in the nineteenth century (Halfpenny and Reid 2002) and voluntary and municipal facilities formed the two types of hospital services; each had different origins, histories and served different client groups (Powell 1997). Voluntary hospitals provided a better quality of care than municipal counterparts, but they were small, poorly distributed,

had restricted access (Pater 1981) and were inadequately funded (Powell 1997). Although, pre-NHS service provision contained many deficiencies, Powell (1997) defends these services suggesting that judgement should focus on the adequacy of the individual facility rather than collectivist principles. However, many authors do give such a collectivist assessment: -

'The outcome for the hospitals was a collection of independently-managed institutions providing an arbitrary patchwork quilt of services of varying degrees of efficacy, separated and enclosed by financial, legal, medical, residential and occupational barriers' (Moon and Kendall 1993:173)

In evaluating the level of democracy and public involvement in pre-NHS services, public representation and involvement could be seen via the hospital board and the voluntary sector itself. Municipal hospital services operated hospital boards, creating some democratic control. Lupton et al (1998:64) described board membership as limited to the local 'great and the good' with service provision replicating the predominant professional and class elitism within wider society. Many voluntary organisations pre-dated the establishment of the NHS (Hogg 1999) and reflected two separate forms of involvement – voluntary/charity work and Labour movements, each established from different social classes (Lupton et al 1998).

Voluntary and charity work was associated with the middle and upper classes and focused on assisting more unfortunate individuals (Lupton et al 1998). In evaluating these organisations, Lupton et al (1998) recognise social reformers and improvements in the social circumstances of the underprivileged initiated by these movements, however assert much was also concerned in preserving the status quo. By contrast, Labour movements and associated groups, established through poverty and need, did challenge the status quo by advocating social change, equality and self-improvement (Lupton et al 1998). Organisations such as the Socialist Medical Association are identified within this movement (Hart 1994) and specific developments such as the Peckham Pioneer Centre emphasised a self-help philosophy (see Section 3.5).

1.2 A Move to Collective Provision

Wartime demand and continuing difficulties with uneven service distribution proved a successful vehicle for government investment and centralised planning for health services (Boaden et al 1982, Moon and Kendall 1993). However, the main catalyst for health reform came with the publication of the Beveridge Report in 1942, which focused on allying health services and national insurance (Pater 1981). It was, however criticised for a lack of detail (Lowe 1993), particularly in the crucial remit of management (Timmins 1996, Lowe 1993). It was also criticised from a feminist perspective, as the needs of women and children were not effectively realised on an insurance-based scheme (Jones 2000). Furthermore, Nairne (1984) maintained that the public and public interest were obscured by the commitment to patient care.

1.3 Democratic Accountability & Public Involvement within the New Service

The NHS introduced a centralised structure linked to the equitable distribution of resources (Klein 1984). The system also changed the relationship between the public and health services, with individualised care giving way to collectivist and universality values (Lupton et al 1998). A tripartite system of services including local authorities, health services and general practice emerged. In reality the service was to become highly fragmented (Boaden et al 1982, Hogg and Williamson 2001). Professional resistance to the national service led to a number of crucial concessions by the government (Lupton et al 1998, Webster 1998) that were to have a permanent effect on the management and direction of the new service (Strong and Robinson 1990, Moon and Kendall 1993) including the level and type of public involvement within its structure. Importantly, there was the loss of local authority control over health provision (Moon and Kendall 1993), which compromised democratic accountability and isolated the service from public involvement (Boaden et al 1982).

Medical dominance was reflected on hospital boards and non-elected lay board members 'operated more as the agents of the Minister for Health than as local representatives' (Lupton et al 1998:64) or governed in name only (Strong and Robinson 1990). Although the establishment of the NHS introduced an upward accountability to the Secretary of State (Barnes 1997, Hogg 1999), the medical professions was self-regulating (Strong and Robinson 1990). Furthermore, the Minister of Health had no powers to remove doctors from service (Pater 1981). Such

factors compromised the public accountability of individual practitioners as well as the service itself (Commission for Representing the Public Interest in the Health Service 1999).

With the establishment of the health system people were seen as passive recipients of health care (Le Grand 2000), with the supposition that they had neither the interest nor the capacity to contribute to its operation (Richardson 1989). The new NHS followed a traditional social administration model of policymaking (Sanderson 1999, Le Grand 2000). Developing a 'bureaucratic-professional alliance' (Davies 2003:198), a co-existent nature (Clarke 1998) where the decision-making process focused on professionals and experts, informed by objective knowledge (Sanderson 1999). Klein (1984:17) described the NHS at this time as 'a monument to the values of enlightened paternalism', where experts, professionals, politicians and managers were seen best suited to address consumer needs (Richardson 1989). Strong and Robinson (1990) also observed that the NHS offered an impersonal service with little choice.

Indeed, practitioners were afforded total clinical freedom, with Harrison et al (1992) describing the profession as a state-licensed elite. Lupton et al (1998) identify the subtle terminology relating to access - the establishment of the NHS gave the right to access health services, rather than the right to healthcare itself, doctors continued to be the gatekeepers to treatment. Furthermore, Strong and Robinson (1990) highlight a user reliance on service providers - the lack of biomedicine knowledge led to services being shaped by suppliers. Such clinical dominance also compromised the ability of central authorities to determine objectives, priorities or expenditure (Lupton et al 1998). However, within a system of limited resources (Powell 1997), Strong and Robinson (1990) argue clinical freedom and gatekeeping potentially provided a barrier to unnecessary and expensive interventions.

1.4 Public Interest & the new Voluntarism

The voluntary sector, itself, had fought the concept of nationalisation (Timmins 1996) and although the traditions of self-help and voluntary work remained following the service's inception, there was no clearly defined role for the sector (Lupton et al 1998). However, public interest in the NHS and new specific roles for voluntary

groups and organisations were to become evident. Although, public involvement is sometimes described as a 'child of the sixties' (Beresford and Croft 1993:7) as early as the 1950s there was public recognition of a developing crisis within the welfare state (Jones 2000). Maynard et al (2001) identify the belief that once the backlog of unmet need was addressed by the new service, demand would plateau in the 1950s. However, a continuing mismatch between demand and available resources became evident within this decade (Milewa 1997). Although the decade saw the emergence of community participation projects, which were found to be more successful and democratic than other projects (Backett 1989 cited in Adams 1995), there was a change within the political and economic environment (Lowe 1993). The financing of rearmament for the Korean War required the control of other aspects of public expenditure, which included the NHS (Lowe 1993).

Richardson (1989) suggests the source of an increase in public interest is not easily traced but it may have been linked to a fundamental change in public attitudes towards authority, with a resistance to decision-making by proxy. Sanderson (1999) supports this view suggesting that medical dominance and bureaucracy had led to public disempowerment. Other explanations suggest disillusionment with aspects of modern medical care and an increase in public expectation (Jones et al 1987, Le Grand 2000). Government and professional notions of individual responsibility in relation to health, meant that consumers were no longer passive recipients of professional care and had become much more questioning (Jones et al 1987, Le Grand 2000). Furthermore, policy assumptions that professionals would always act within the public interest were beginning to be undermined (Le Grand 2000) - much of the public concerns stemming from a number of service scandals.

New voluntary organisations such as the Consumer's Association and Patient's Association were emerging in the 1960s. Jones et al (1987) identifies that the consumer movement participated in a number of pioneering studies in consumer response developing literature relating to health services and publications dedicated to enhancing public influence in such services. The Patients Association, established in 1963, represented the patients' interest as a whole and focused on concerns over service failures and scandals (Boaden et al 1982). Direct experiences in dealing with or working for professionals had led lay people to observe professional self-interest at

first hand (Le Grand 2000). However, the public was defined primarily as patients within the association reflecting a limited focus (Boaden et al 1982).

Health issues were seen as a lower priority within the 1960s (Webster 1998, Lowe 1993) with continuing geographical and social inequalities (Webster 1998) compounded by an ageing population (Lowe 1993, Allsop 1995). As in the 1990s, there was a refocusing on primary and community care with proposed initiatives to move some hospital patients back into the community (Lowe 1993). Community-based care was combined with the 'Hospital Plan' in 1962, where poorly equipped and unevenly distributed hospitals were to be closed or modernised. Over a thousand local hospitals were closed, causing public protest (Webster 1998). However, Webster (1998) identifies that of the 250 new/modernised district general hospitals proposed, only one third were completed by 1979; community care initiatives stalled, with shortfalls in alternative accommodation and staffing (Lowe 1993).

Lupton et al (1998) also identified the development of government-sponsored community participation within this period. It is suggested that this was a deliberate policy and a political response to perceptions of increased public dissatisfaction with services and inner-city social unrest as well as an attempt to address 'passive citizenry' - a public making increasing demands on services without becoming actively involved (Lupton et al 1998:70). The 1960s also witnessed the Ely Hospital scandal, the report was published and made available to the public in 1969 and reflected institutionalised neglect, brutalisation and humiliation of long stay patients with learning disabilities (Webster 1998, Foster and Wilding 2002). Such incidents were to undermine public confidence in health services and also seemed to mark the end of a golden era for the medical profession in relation to public support (Foster and Wilding 2002, Davies 2003). Professional accountability was being questioned as well as the rights of service users (Foster and Wilding 2002). Lowe (1993) also concludes that there was a general failure of politicians to engage with such health care issues, favouring short-term rather than long-term actions, political disengagement provided a gap that was filled by voluntary organisations.

1.5 Public Involvement in the 1970s – redefining lay involvement

Expansive social policy, in relation to service development, was impeded by economic crisis linked to the devaluation of Sterling, an oil crisis and industrial unrest (Webster 1998). Against such a social and economic backdrop, this decade saw the long awaited reorganisation of the NHS in 1974. Klein (1984) maintained the reorganisation heralded a new structure, representing an attempt to bring the organisation closer to its original aspirations, linking medical expertise and bureaucratic rationality (Webster 1998). However, the reorganisation was to be viewed as a failure, with no clear lines of leadership or accountability (Lupton et al 1998) and too many tiers of administration (Lowe 1993).

The nature of public involvement was to change within this new structure. In trying to produce more competent boards, appointments were to prioritise people with business experience (Lupton et al 1998). However, Lupton et al (1998) maintain that few people with business skills were actually appointed to boards and many within government and the service felt that such appointees typically lacked knowledge of the healthcare service. The reorganisation also saw a further loss of local authority control (Boaden et al 1982) with public and community health services incorporated within the service resulting in a more medically dominated approach to care (Lupton et al 1998).

Government reactions to public scandals and inappropriate care lead to a number of developments. The position of Health Service Commissioner was introduced in 1973 (Lupton et al 1998). As with many government initiatives the health ombudsman lacked real power within the medical domain with authority confined to non-clinical areas. Furthermore, the Commissioner could only act after the event and complainants had to navigate a lengthy and complex procedure (Lupton et al 1998). Boaden et al (1982) suggest that the focus on individual complaints, mostly from the middle classes, impacted on the type of public participation, limiting the pressure for more general change. Community Health Councils (CHCs) were introduced within the 1974 NHS reorganisation. The CHCs were a reaction to public scandals (Hogg 1999) as well as recompense for a decrease of local authority representation at board and committee level within the NHS (Allsop 1995, Webster 1998).

1.6 Community Health Councils

CHCs gave expression to the need for the public interest to be represented to health professionals and decision-makers (Barnes 1997:8) and were also viewed as local watchdogs (Allsop 1995), working as a committee of lay people to safeguard patients through increased public involvement and scrutiny (Hogg 1999). Disappointingly, the development and implementation of Councils was described as 'back-of-the-envelope planning' (Hogg, 1999:90), with little thought given to function or accountability. CHCs had rights to visit hospitals, to access information and to attend health authority meetings as well as management consultation in relation to service changes (Hogg 1999). Unfortunately, there was little guidance either for managers or CHCs on how these rights were to operate which caused recurrent arguments in relation to interpretation (Hogg 1999). Involvement in local services was also linked to a non-challenging approach and statutory status brought the need to behave responsibly (Boaden et al 1982).

Representation was to remain a continuing thorn in the side of the councils, as CHC boards were again non-elected (Boaden et al 1982). Representation was unsystematic, with the same organisations persistently represented, with suggestions that nominees pursued their individual specific interests rather than wider issues (Commission for Representing the Public Interest in the Health Service, 1999). Furthermore, nominees were often already well known within the service or were already concerned with health services (Boaden et al 1982). In addition, many groups assumed strong professional characteristics, with a middle class and middle-aged composition (Klein and Lewis 1976, Boaden et al 1982). Inadequate representation led councils to seek legitimacy and influence through expertise (Boaden et al 1982). However, their accountability was compromised with individual councils interpreting their functions differently (Hogg 1999) (see Section 3.3).

Webster (1998) in analysing the new tier system within the NHS identified a gender imbalance within the NHS structure with a lack of women in chair positions at Area Health Authority and Regional Health Authority levels. The only location where women achieved substantial strength was in CHCs (see Klein and Lewis 1976), a

relatively powerless position (Webster 1998). However, CHCs were involved in groundbreaking work, which was later adopted by the health services (Hogg 1999) this included: -

BOX 1

CHC Initiatives

- Support for community networks and self-help groups
- Advocacy schemes
- User surveys
- Research on the unmet needs of disadvantaged groups
- Patients' charters
- Provision of information and advice (Hogg 1999:90).

However, CHCs would have to resist a number of attempts at abolition (Hogg 1999) over the next two decades, perhaps linked to government and managerial concerns on the political nature of CHCs (Lupton et al 1995) as well as suffering from persistent low public awareness (Buckland et al 1994). Both mechanisms, CHCs and Health Commissioner reflect reactive policy formation. More fundamental, perhaps, is the question of why these central initiatives had such extensive limitations placed on them by government. Again it seems health policy making maintains the status quo between public demands and vested service interests, particularly those of the medical profession.

1.7 Community Development, Voluntary Activity and General Practice

The 1970s witnessed some short-lived community development initiatives (Lupton et al 1998) and although general practice had remained relatively untouched by growing interest in involvement in the 1960s (Brown 1999) the decade heralded patient participation groups (PPGs). This was a professionally initiated movement (Wood 1984, Richardson and Bray 1987 cited in Brown 1999). The main focus of PPGs was the meeting of patients, doctors and practice staff in the interests of improving communications and services (Wood 1984) and a National Association of Patient Participation Groups was formed in 1978 (Brown 1999). Both PPGs and community

development initiatives can be related to the Declaration of Alma-Ata in 1978, which linked the idea of public participation to health care (Adams 1995).

'The people have the right and duty to participate individually and collectively in the planning and implementation to their health care' (WHO 1978, Part Four cited in Adams 1995).

The declaration allied government commitment to the development of primary health care strategies by facilitating community and individual participation in the planning and development of primary health care (Wood 1984). However, PPGs suffered from a number of difficulties, professionally initiated, the groups had inadequate representation and were unevenly distributed nationally (see Section 3.4).

Voluntary activity continued to expand within the same period, with an increase in disease-related patients associations (Wood 2000). Wood (2000) asserts their growth and development did not lead to greater political effectiveness and Sanderson (1999) suggests that the images of these particular groups supported assumptions of helplessness and dependency. Such organisations were not seen as full partners in health care decision-making and were largely ineffective as pressure groups (Wood 2000). Images of partiality and self-interest as well as the restraints of charitable status did not assist their objectives (Wood 2000). Often, such groups represented a type of collective or class advocacy (Simons 1993, Teasdale 1998). Such advocacy focused on developing public support or campaigning for a group or class, usually as established organisations (Simons 1993) e.g., Multiple Sclerosis Society.

The late 1970s saw the development of Joint Consultative Committees (JCC) to facilitate closer cooperation between local and health authorities and produce effective joint plans for interdependent services (Lupton et al 1998:70). Although JCCs had lay representation, they were described as cumbersome (Webster 1998) with lay members having to negotiate highly jargonised meetings (Brotchie and Wann 1993). Joint planning initiatives also fostered the development of specific care groups such as those for mental health, physical disability, learning disability, elderly,

children and families and again focused the activities of voluntary groups in similar ways (Lupton et al 1998). It again reflected a sector that was itself developing reactively and strongly influenced by the implementation of health policy and developments within the health service itself. The strong emphasis on disease or categories of patients parallels the predominance of the medical model within health care at this time. Boaden et al (1982) echo the view that such organisations had very little political effect, with many groups remaining isolated from collective strength with professionals often playing key roles.

1.8 Challenging Welfare Provision

Economic crisis in the early 1970s was a crucial factor in a change of political and public opinion regarding state welfare (Jones 2000), publications such as the Black Report (Timmins 1996) identified continuing inequalities despite state provision (Lewis 2000). Challenges to state provision came from contrasting political directions, from the 'New Right' as well as radical Marxists and new social movements (Sanderson 1999, Lewis 2000). Both ideologies were to directly affect the way public involvement was defined and developed within the next two decades. They were to confront the relations between state, people and social welfare and the relative distribution of rights and responsibilities (Lewis 2000).

Lewis (2000:16) identifies, within policy analysis, the importance of identifying which social divisions/problems are seen as the concern of policy makers and why. By the end of the 1970s there was a policy shift refocusing on individual blame (Allsop 1995) with the suggestion that the health service could function more effectively if the public adopted a healthier lifestyle (Webster 1998). New Right policy emphasised self-reliance (Sanderson 1999) and this impacted on social relations of care as people were expected to be self caring and professionals were seen as playing a more secondary role (Jones 2000).

Indeed, the issues raised within the Black Report were not universally accepted as a high priority and the Conservative government ignored its policy initiatives and public expenditure commitments (Allsop 1995, Webster 1998). However, the development of New Social Movements (NSMs) challenged the status quo and the

notion of victim blaming. Such groups advocated user rights, pushed for greater social integration and were opposed to traditional voluntary organisations (Barnes 1999). Both ideologies, either through the notion of consumerism or self-advocacy, allied themselves to increased user involvement in healthcare decision-making (Barnes and Warren 1999).

1.9 The Emergence of Managerialism & Economic Discourse

The election of the Conservative party in 1979 made a major impact on welfare provision, with the emergence of an 'individualist ideology' attacking collectivism (Jones 2000). The 1982 NHS reorganisation saw a move away from the principles of expertise and bureaucratic rationality seen in 1974, with the Griffiths Report proposing the replacement of professional paternalism by managerial authority (Klein 1984, Jones 2000). Allsop (1995) describes the changes that took place as the most radical since the creation of the service, a reaction to a professionally dominated, unresponsive and inefficient system, Foster and Wilding (2002) also identified New Right assertions that the national service was a monopoly lacking competition and advocated increased operational efficiency (Jobling 1989).

Joyce (2001) maintains the NHS reforms were part of a shift to a neo-liberal formula of governance, which expressed a free market rationale as the foundation of social policy, the function of the health system was linked predominantly to an economic discourse. Clarke (1998) states that the New Right ideology was insistent on the inherent supremacy of the market for resource allocation; doctors were to be drawn into management and could no longer ignore the financial consequences of their decisions. The Griffiths Report was to change the direction of NHS managers who were to become more business-like (Allsop 1995), with public involvement becoming a management responsibility (Taylor 1995, Rhodes and Nocon 1998). Waine and Henderson (2003) identify the key features of managerialism as provider/purchaser split, quasi-markets, competition between service providers with an emphasis on consumers of services and performance management. These features and their impact on public involvement are discussed in the following sections.

1.10 The Public as Consumers

Klein (1984) identifies the key elements in linking consumerism with the NHS - consumerism relates to value for money, individual decision-making from informed choice, concentrating on the consumer's experience of health care (Klein 1984). Sanderson (1999) maintains this changed the relationship between NHS organisations and the public, with the relationship now seen primarily in economic terms, with 'choice' presented as an end in itself. However, Jones et al (1987) suggest that the public exhibited a lack of information seeking and consumer-orientated behaviour and the concept encouraged a focus on demand, but failed to emphasise the publics' responsibilities (Coulter 1999a:719).

1.11 The Quasi Market

The NHS reforms also heralded the internal market system (Gurney, 1995), however the attempts to introduce market mechanisms contributed to a loss in public confidence (Barnes 1999). In reality, competition was weak (Dixon and Mays 1997). Klein (1984) observed that equity in the market place is irrelevant, but central to the NHS; a private firm disregarding consumer preferences would lead to bankruptcy but there was no corresponding sanction in the NHS. Indeed, Sanderson (1999) identified the system was inherently inefficient due to the absence of the conditions of incentives and sanctions associated with market forces.

1.12 Purchaser/Provider Split & GP Fundholding

Harrison and Pollitt (1994:127) suggest that the particular approach to the purchaser/provider split adopted in the UK did not empower consumers directly but rather empowered their agents. With the purchaser provider split, came the emergence of NHS and Community Trusts and GP fundholding – all three were to compete in the provision of health care (Shackley & Ryan 1993). Sanderson (1999) suggests the outcome was to increase the distance between purchaser and user, reducing the power of the user to influence services. However, Gurney (1995) argues that resource allocation became more overt, with the public gaining access to contracts between such purchasers and providers and there were statutory requirements for purchasing authorities to consult widely, but no clear strategy for consultation emerged (Gurney 1995, Bowl 1996). Hogg (1999) counters Gurney (1995) by maintaining that the internal market introduced and justified more secrecy in trusts rather than openness as

many NHS providers held board meetings in secret, deemed to be for commercial reasons due to competition with other providers (Hogg 1999).

Lupton et al (1995:218) describe 'executive-style boards, which were subject to central political control, with the notion of local accountability effectively abandoned'. A code of openness was launched for the NHS in 1995 (Hogg, 1999:85) outlining the need for public access to information about the NHS. In reviewing 'The Code of Practice on Openness in the NHS' (NHS Executive 1995) the document reflects a complex system, where the individual has to make a written request or a request in person to gain access to information. It is clear from the document that organisations and individuals still have the right to withhold information, but now had to offer some explanation within three months of the request.

GP fundholding enabled GPs to purchase services for their practice patients. However, due to their independent contractual status there was limited government control over their actions (Hogg 1999). Furthermore, fundholding resulted in a great disparity in the standards of service provision with an emerging two tierism (Leese et al 1999, Roland 1999) and produced further inequalities between practices (Allsop 1995). Although health authorities monitored and facilitated fund holding they had no powers to take action in relation to failing standards (Hogg 1999). In addition, GP fundholders were relatively indifferent to needs assessment, with priorities predominantly medical (Fisher and Gillam 1999). Montgomery (1992) claimed the system ingrained the belief that doctors could act as proxy users. However, Harrison and Pollitt (1994) acknowledged that changes in the GP contract meant that patients no longer needed to seek their GPs approval before registering with another practice suggesting GPs would be more keen to respond to patient preferences rather than lose patients and income. However the authors highlight a lack of accessible alternatives in many areas, which undermined a shift of influence towards patients (Harrison and Pollitt 1994).

1.13 Accountability & Choice

It was increasingly difficult for the public to become involved in the planning and monitoring of local health services as the reforms had created complex new structures, there was no longer one health authority but NHS trusts, voluntary and private sectors providers and primary care commissions (Hogg 1999). The mixed economy also led to the further fragmentation of services and Sanderson (1999) argues this disempowered the public further as dispersal made access and control over organisations more problematic. The changes within the NHS structure did not extend to the CHC, Lupton et al (1995) highlight that government circulars and guidance of the time served to constrain CHCs, again involvement was left to the discretion of local health authorities. Importantly CHCs had no rights to visit GP practices and requests that fund holders be required to establish effective liaison arrangements with CHCs had been rejected by the government (Lupton et al 1995).

Although Brotchie and Wann (1993:6) assert the lay person became a more important player in health policy at this time, this is challenged by a number of authors. The Griffiths Report was criticised for vague references to wider public involvement (Harrison and Pollitt 1994, Lupton et al 1998, Barnes 1999). 'Working for Patients' (DoH 1989) stressed increased service choice and increased patient autonomy and 'The Health of the Nation' (DoH 1992) promoted public involvement in decision-making, specifically options and prioritisation. However there was little evidence that this occurred and little attention given to the role of the consumer within health policy (Shackley & Ryan, 1993).

Public involvement initiatives took a low priority, with public consultation having little effect on major decisions (Rhodes and Nocon 1998). Importantly, management-led consultation initiatives meant management determining how to use such information (Harrison and Pollitt 1994). Consumer choice was used divisively to counter professional power and authority, perceived as the major obstruction to organisational change and to curtail GP referral freedom (Rhodes and Nocon 1998). Management could use consumer authority to counteract professional claims to knowledge of client needs (Harrison and Pollitt 1994, Rhodes and Nocon 1998). Although there was a move towards localisation of priority setting and decision-

making, this was increasingly contradicted by a tendency towards centralisation (Jobling 1989), particularly control over policy and strategy (Hughes and Griffiths 1999). There was no mechanism for purchasers to be held accountable to local populations for their decisions with little public influence - choice remained with GPs and consultants (Allsop 1995, Milewa 1997).

1.14 New Social Movements & Self Determination

The 1980s also saw the development of new organisations and movements of people who used health and welfare services (Beresford and Croft 1993). A number of major themes emerged from these new social movements (NSMs) focusing on self-definition, self-determination and advocacy, emphasis was placed on users and survivors developing their own identity (Barnes and Bowl 2001) and addressing unrecognised inequalities (Lewis 2000). This is perhaps a reaction to the propensity of statutory and voluntary organisations that categorised groups of users (Woods 2000, Lupton et al 1998) with the use of client and disease groups impacting negatively on user definition (Sanderson 1999).

NSMs advocated active citizenship, reacting to the rule bound and authoritarian bureaucracy of New Right policy, with demands for negotiation and more democratic and dialogic ways (Sanderson 1999) of interpreting and meeting need, with a more holistic view to users (Lewis 2000). Self-determination and advocacy focused on the right to have control over their lives (Lupton et al 1998) with arguments that services should facilitate individual decision-making rather than providers doing things to or for users (Barnes and Bowl 2001). Although developing mainly in the 1980s, some pioneering work is evident in Great Britain in the early 1970s by the Campaign for Mentally Handicapped People and initiatives such as 'We can speak for ourselves' and 'People First of London' (Hersov 1996).

The organisations themselves reflected a diverse client group and Barnes and Warren (1999) assert related services established different relationships between service users and providers, meeting needs that had been previously been ignored. Such groups were locally based, providing support and information, but were susceptible to change, particularly if externally funded (Barnes and Warren 1999). An example of precarious funding can be seen with the reduced budget for HIV and Aids services by

the Department of Health, causing a ripple effect with some health authorities reducing or withdrawing funding affecting organisations such as London Lighthouse, Terrence Higgins Trust, London Body Positive (Hirst 1996). NSMs developed in opposition to traditional voluntary organisations, which were criticised for claiming to act for specific users, however users did not directly control them (Barnes and Warren 1999). In response to user criticisms, some charities began a process of changing organisational structures and developing strategies to include the views and opinions of their service users at policy and decision-making level (Thompson 1999).

New philosophies emerged within these social movements; the theory of 'social role valorisation' or 'normalisation' stressed social integration and a valued life for people (Beresford and Croft 1993). Sanderson (1999) also identifies a social constructionist perspective, with the need to recognise the construction of alternative realities by different stakeholders, holding different forms of knowledge. An ideological example is seen in the emergence of the disability movement, which identified the politics of disability based on a critique of existing services (Davis 1999). An alternative service structure devised by disabled people themselves was envisaged (Davis 1999). Although the Disability Discrimination Act of 1995 was strongly criticised (Davis 1999), the Disability Rights Commission came into effect in 2000, its remit to enforce rights and lobbying with a disabled person as chair (Huber 1999). There was also the development of informal confederations representing disabled people, aiding collaboration with statutory and voluntary agencies (Barnes and Warren 1999).

1.15 Changes within Community Care

Community health action initiatives were also becoming prevalent in the 1980s (Brown 1999) and had many similarities to the development of the NSMs emphasising self-determination. The principles of such initiatives were made clear in the World Health Organisation's 'Health for All 2000', which focued on the role of the community working with health professionals (Lupton et al 1998). However, Lupton et al (1998) describe the Conservative government's reaction to such initiatives as complacent, unsupportive and ignoring many central issues.

Health policy, at this time, identified a central role for the voluntary sector. Within this neo-liberal ideology, the sector emerged as providers, particularly for those whose needs could not be met by the market (Halfpenny and Reid 2002). The National Health Service and the Community Care Act (1990) saw the creation of competitive markets in health and social care (Jones 2000) designed to encourage voluntary and non-profit organisations to compete with private and statutory sectors in service provision (Lupton et al 1998). The effects on voluntary organisations were separation of service provision from campaigning, research and development, however Lupton et al (1998) maintained that innovative services evolved from a combination of these activities. Furthermore, this was a complex and costly system that did little to extend freedom of choice to individuals or noticeably reduce government interference (Jones 2000). Similarly, the CHCs were required to develop good working relationships with their health authority with government directives suggesting an increased role in purchasing, which presented a dilemma for CHCs, between co-operation and independence (Lupton et al 1995).

However, there had been rapid implementation of NHS reforms (Allsop 1995, Light 1999) and the government bypassed the usual channels of consultation (Allsop 1995). The 1980s saw an increase in complaints and growth in private health insurance, perhaps an indication that the NHS was failing to respond to the needs of the public (Lupton et al 1998) and the lack of public consultation. There was a refocusing of government rhetoric on 'quality' and this strategy was used to reassure the general public about the perceived decline in public services and to increase NHS staff morale (Harrison and Pollitt 1994). Quality issues continued to be championed by the incoming Labour government in 1997 (see 'The new NHS: Modern and Dependable, DoH 1997).

1.16 Social Justice, Citizen Rights & Patients' Charters

The 1990s again saw a change in the nature of public involvement with a re-evaluation of citizens' rights. This not only occurred at a national level but was also developed in an international climate and was influenced by the processes of globalisation and regionalisation (Lewis 2000). There was increased international discussion regarding citizens' rights and responsibilities and the development of related charters, such as the European Social Charter, at Maastricht in 1991 (Lewis

2000). On a national level the Citizens' Charter Unit initiative was launched in 1991 (Allsop 1995). However, the Conservative charter gave little discussion to rights instead emphasising privatisation, competition, performance related pay and choice (Coote 1992, Allsop 1995).

The Patients Charter was also launched in 1991 addressing aspects of the Citizens Charter in the health service (DoH, 1995) as well as the publication of league tables in 1994, which enabled comparison of performance against charter standards (Barnes 1999). However, the charter was criticised on a number of fronts. There were problems with speed of its development with a lack of consultation with staff and users and it lacked clear aims with irrelevant standards (Farrell et al 1998). Hogg (1999) suggested that it could be seen as a public relations exercise diverting attention from other problems in the NHS. There was a low patient awareness of the document and the notion of consumerism continued to underpin the charter (Rhodes and Nocon 1998) and there was little emphasis on patient responsibility (Timmins 1996, Farrell et al 1998). The emphasis was on expectations rather than rights (Commission for Representing the Public Interest in the Health Service, 1999). In reviewing the Patients' Charter (1991) such examples of unrealistic expectations can be identified, such as unrealistic maximum waiting times, furthermore, expectations and rights identified were difficult to enforce, although such enforcement was seen as fundamental to citizen empowerment (Coote 1992, Montgomery 1992). The Association for Community Health Councils for England and Wales (ACHCEW) put forward in their own publication 'The Patients' Agenda' (1992) with a comprehensive list of rights but with no tangible impact (also see DoH 1995a).

The Commission on Social Justice, who published their report in 1994, underlined this concern and the beginning of the report is disconcerting and re-echoes concerns of continuing inequalities despite welfare provision: -

'For generations, we have grown up to believe our children would be better off than ourselves. But today, for many people, that assumption has been shattered. Old evils of homelessness and pauperism have returned; new evils of insecurity have emerged …' (Commission on Social Justice 1994:2)

However, this report itself was criticised by the Citizens' Commission (1997), which was created out of concerns regarding the failure to include welfare state service users in discussions.

Social rights to healthcare and welfare services were seen as no less credible than civil rights (Coote 1992, Plant 1992). Such social rights were also seen as central to citizenship (Plant 1992). This dimension of rights played a central role in the United Nations Declaration of Human Rights, to which the Conservative government had committed itself (Montgomery 1992). However, arguments against social rights focused on the scarcity of resources, public expenditure and concerns over the growth of the public sector (Plant 1992).

1.17 Strategic Thinking & Audit

The 1990s saw a two-way policy shift, firstly involving people and communities as citizens in strategic decision-making, which included enhancing accountability, secondly, recognition for the need for partnership with local populations to improve health (Barker et al 1998:8). The first health strategy 'The Health of the Nation' (DoH 1992) appeared, however it was formulated without systematic input from the citizens whose health it targeted (Bradley et al 1999). Furthermore, the NHS came under external scrutiny from the Audit Commission, which had been established to audit local government but extended its remit to the NHS in 1991 (Klein 1999). The Commission was capable not only of assessment of service provision but the type and level of public involvement. However, the agenda of the Commission was set by it's own board and Klein (1999:9) suggests a paradox with audit of a national service carried out by a 'quasi-autonomous body'. Furthermore, the objective of the Commission was to inform those who were audited, however there were no clear lines of responsibility to implement any recommendations (Klein 1999).

Power (1999) cited in Clarke (1998) also identifies the audit explosion, indicating the growth in both internal and external evaluations of performance and compliance. This was viewed as a strategic response from the centre aimed at extending the disciplines available to regulate the periphery, Clarke (1996) views this as a way of overcoming increased fragmentation of services. However, the process of audit transferred scarce

organisational resources from service production and delivery to information and monitoring systems (Clarke 1998).

1.18 Local Voices

The publication of the government document 'Local Voices' occurred in 1992, advocating public involvement in a number of areas such as needs assessment, purchasing, priority setting and service development. The document suggested that health authorities should take on 'a champion of the people role' (NHS Executive, 1992:3) a role traditionally linked to Community Health Councils (Lupton et al 1995). However, the statement was criticised as absurd, as there was a conflict of interests linked to the financial imperatives of health authorities (Commission for Representing the Public Interest in the Health Service, 1999). Importantly, it was to herald a change in focus, from predominantly user involvement, to taking into account the views and preferences of local people (McIver 1998:4). This approach would enhance the credibility of the health authority and would result in more appropriate services (DoH 1992). However, Milewa (1997) suggests that 'local voices' was designed to raise popular awareness of the need to prioritise services rather than for active involvement in the determination of priorities. This is further supported by Joyce's (2001) suggestion that the concepts of priority-setting and explicit rationing became embedded as dominant discourses and emergent practices within health policy.

Reactions by health authorities to 'Local Voices' are reflected in such documents as 'Listening to Local Voices' (National Association of Health Authorities and Trusts (NAHAT) 1993). The document also suggested the development and implementation of a public participation strategy. However, the rhetoric continued to reflect the focus on the internal market and consumerism. Clearly, the aim was information dissemination regarding the operation of the internal structure and the methods again reflect information gathering and dissemination and were not particularly participatory.

Such observations are underlined by NAHAT (1993) in its description and focus of a public participation strategy: -

BOX 2
Public Participation – A Health Authority Approach

- The image of the NHS, the NHS authority and its proposals
- The internal market, the role of trusts and fundholding general practitioners, and how the market may develop to the advantage or detriment of local people
- The need to generate awareness of the issues, of the NHS authorities' role, and to establish 'ownership' of key concerns amongst the population
- To be clear about the appropriate focus of an issue – whether this is a client group, a minority community, or broader social policy
- The methodologies to be employed, whether these are public surveys, community meetings, search conferences, rapid appraisal or other techniques for public involvement
- To be sensitive to local factors, to respect individuals, to recognise the need to discuss ethical conflicts which may arise in the development of health priorities (NAHAT 1993:13)

Publications within this period reflected the terminology of ownership, stakeholders as well as the re-emergence of the concept of partnership. Such terms suggest the relationship between the public and the NHS was not only one of involvement but of mutual responsibility.

1.19 Partnership, Principles & Empowerment

Policy review in the early and mid 1990s identifies that empowerment was linked to access to information and a series of listening exercises within the 1990s involved patient organisations and professionals (Gann 1998). Community involvement and primary care were also to re-emerge in health policy, community development was the central theme of the Building Partnerships for Success – Community Development Programmes (DoH 1995b) cited in Davies and Little (1996) and a number of pilots within primary care were initiated e.g., total purchasing pilots, commissioning pilots, Personal Medical Services (PMS) pilots. Again the pilots reflected a policy focus of 'consumer choice, provider autonomy and professional opportunity' (Meads 1999:96). Such primary care organisations were emerging in the 1990s in some areas as new collective and alternative arrangements (Meads 1999, Smith 2000). However, review of such pilot schemes showed a lack of public involvement (see Section 3.4) with developments basically determined by economic and clinical imperatives (Meads 1999).

The Nolan Committee's first report on Standards in Public Life was also made available in 1995. This was a six-month inquiry, initiated by the Prime Minister, focusing on standards in public life, following a number of public scandals particularly relating to commercial interests and public disquiet surrounding acceptable conduct. The report included executive Quangos and NHS bodies and identified seven principles of public life: - selflessness, integrity, objectivity, accountability, openness, honesty and leadership. The report findings, which included NHS bodies, suggested that appointments to boards were not always made on merit. The report also suggested a new independent regulatory body, the Office of the Commissioner for Public Appointments (OCPA) to monitor and report on the appointment process, the regulator was to support the NHS Appointments Commission established in 2001 (see Chapter Seven & Ten).

Following the links between empowerment and information, a plethora of government documentation relating to user and public involvement with strong links to information appeared in 1996. The National NHS Patient Partnership was developed in 1996 as a way of improving access to good quality clear information about services and treatment and again information was linked to increased empowerment (Gann 1998). The strategy established the National Patient Partnership Reference Group (Barker et al 1999), the influential publication 'In the Public Interest' (NHS Executive/IHSM & NHS Confederation 1998), the establishment of the Centre for Health Information Quality (CHIQ) and support for the Health Information Service. Furthermore, 1996 saw the establishment of The Standing Advisory Group on Consumer Involvement in the NHS Research and Development Programme (Barnes 1999:13). Its remit was to ensure that consumer involvement influenced the way in which research was prioritised, commissioned, implemented and disseminated (NHS Executive 1998). Again the initiatives focus strongly on information exchange rather than active participation (see Section 3.7.3) and information centres remained underutilised.

The NHS Executive booklet 'NHS Priorities and Planning Guidance' also appeared in 1996. The document focused on giving a greater voice and influence to users and carers (Allen 1996) specifically in relation to care, setting standards and policy development (Gann 1998), indeed, public involvement formed one of the key six

objectives for the Government's medium priorities (Barker et al 1999:8). The booklet recommendations mirror those within the government guidance to PCGs in relation to public involvement (HSC 139:1998). Strategic planning with systematic and continuous communication with users, carers and the public, demonstration of the impact of consultations as well as adequate feedback and training for professionals who had substantial contact with users were all identified (NHS Executive 1996). However, Barker et al (1999) argue that there had been limited consultation involving the wider public or explicit priority given to public involvement. It is disappointing that there is little evidence within this hectic period to suggest that such guidance was fully implemented and reflects a worrying policy trend - where needs inherent in public involvement are clearly, if not tediously, restated but not acted upon.

Summary

Public involvement and democracy have proved difficult bedfellows for the NHS, with the structure and organisation of the service having a major impact on both concepts, within and outside the new system. The impact of a social administrative model and a series of concessions to the medical profession led to a professionally dominated service, with the displacement of both local authority and voluntary control of healthcare and a 'public' viewed as passive and disinterested. The historical perspective has shown that the issues of democratic accountability, clinical freedom and self-regulation have remained relatively unchanged and the service has been described as the least accountable of Britain's major public institutions (Commission for Representing the Public Interest in the Health Service, 1999).

This analysis has also identified reactive, compromising and, sometimes, divisive policymaking. Often attempts at increasing public involvement were instigated to regain public confidence in scandalised services or to erode medical dominance. However, within a changing political, economic, social and cultural backdrop, paradoxically this perspective revealed a number of remarkably consistent themes. Policymaking continued to reflect ambiguity in relation to public involvement particularly its operationalisation. Poorly funded and under resourced initiatives were persistent with an ad hoc or short-lived approach to many developments evident. Medical dominance remained relatively intact as well as the continuing resistance of the wider general public to get involved. Such observations highlight not only the

complexity of public involvement throughout the fifty years of the health service but also differing governmental, professional and lay attitudes to the publics' role in relation to this concept.

Finally, health policy has engaged in the persistent redefining of the term 'public', documents reflect a diversity of terms, such as patient, user, consumer and citizen. Equally there have been different perspectives on 'involvement' with terms such as consultation, partnership, participation and involvement utilised. Importantly none have been clearly defined and all reflect different levels of participation and empowerment. Before presenting the analysis of emergent health policy by the New Labour government and its vision of a new NHS (see Chapter Four), Chapter Two gives a detailed discussion of definitions of public involvement, the concept's implementation and the, often understated, importance of cultural change and power relations. Chapter Three presents research evidence regarding public involvement, aspects of which may have formed the basis of policymaking within the new NHS and primary care specifically. As such, the next two chapters provide the crucial context in which to place policy formation and implementation relating to primary care and public involvement.

CHAPTER TWO

Definitions, Implementation & Power Sharing

Introduction

A review of health policy and associated literature reflected the seemingly boundless potential of public involvement. However, such advantages were expressed without any clear or stable definition of public involvement. Chapter One reflected such ambiguity. Historically the concept was linked to changing descriptions, the public moving from passive recipient to active citizen and involvement repackaged as consultation, engagement, empowerment or partnership. Potentially, changes in terminology are unproblematic; such changes could reflect a service reacting to cultural, social and political forces. It is the persistent failure to adequately define and elucidate on such terms, which is the real policy weakness. Therefore, an analysis of 'public' and 'involvement' was essential in understanding this complex area.

Further difficulties relate to the operationalisation of public involvement. A strategic approach, with an on-going consultative relationship with the public was advocated within government directives (NHS Executive 1992, HSC 139, 1998) but again, frustratingly, 'strategy' has its own definitional difficulties (Joyce 1999). Chapter Two attempts to gain some clarity in relation to implementation. It acknowledges the potential difficulties in developing an effective public involvement strategy and focuses on process as well as outcome in attempting to identify essential factors relating to its successful implementation. However, the review also accepts that without commitment to cultural change and power sharing public involvement would ultimately fail to deliver wide-ranging benefits. The final section focuses on power and associated concepts, with an analysis of power relationships within the health service and their potential to effect involvement.

2.1 Defining Concepts – Who are the public in public involvement?

Lenaghan (1999:10), in analysing assorted white and green papers, suggests that terms such as citizens, users, consumers and community have been used interchangeably with limited awareness of the different strategies associated with different public capacities. In examining definitions of public involvement, its related

diversity of meaning and purpose was immediate. The need for a plan of approach was also evident and this review was influenced by the work of Gurney (1995) who, in his own exploration, divided the concept into two constituent parts. The following sections explore 'public' and 'involvement' as distinct parts before culminating in an analysis of differing conceptual combinations utilised in government policy and related texts.

Gurney (1995) asserts that defining the public is important in establishing who should be involved. However, he suggests that a broad definition, which could include everyone, is strategically unworkable – as Jakubowska (1999:7213) observes 'the public does not exist as an entity'. The literature review identifies many different potential participants often categorised within individual, group, community and organisational boundaries (NHS Executive 1992, HSC 139 1998, Coote 1999a, Wright 1999), more vague are the terms 'general public', 'wider population' or simply 'the public'. Within an individual context, potential participants specifically linked to the NHS were service users, lay members and non-executive directors, however the terms consumer and citizen have also been visible within health policy from the 1980s onwards (see Sections 1.10 & 1.17).

Coote and Lenaghan (1997:i/ii) identify the 'complex identities' of the public, perhaps more accurately multiple identities, where a person can be active within a number of categories simultaneously – individually, within a group, community or organisation. These identities are obviously interchangeable and fluid dependent on circumstance and interest. Such boundaries, therefore, can be merely conceptual rather than physical, however it also becomes clear that members of the public need to know the capacity of their involvement – user, citizen, consumer? Different capacities are not only linked to different methods of involvement (Lenaghan 1999) but different rights, roles and responsibilities (Lupton et al 1995:216).

2.1.1 Challenges of Duality – user versus citizen

Lenaghan (1997) recognises a dual relationship between the public and the NHS, as service users and citizens; each identity has different and often conflicting interests. Citizens have been defined as all those for whom the state has responsibility for

ensuring health and providing healthcare when it is needed (NHS Executive/IHSM and NHS Confederation, 1998:35). The importance of separating these capacities is emphasised by Lenaghan (1997), users have a direct and individual interest in a specific service (see Fleming and Golding 1997, Herxheimer and Goodare 1999 and 'Patient and Public Involvement in the new NHS (1999a)). The capacity of citizen moves beyond self-interest, with concern relating to family, the local community and fellow citizens, in the present and future (Lenaghan 1997) – it is this capacity which interests this research project. Furthermore, Lomas (1997) identifies the potential inconsistency between preferences made within user and citizen capacity, which is complicated by a lack of clarity by organisers of initiatives, who fail to identify the role individual participants should adopt. The identification of members of the public as consumers rather than citizens, also suggests different roles, rights, responsibilities. Citizen and consumer are incorporated into two models of involvement, which have influenced health policy.

2.1.2 Consumerist and Democratic Models of Public Involvement

The two models identified within the literature are democratic and consumerist and a key factor is where the model positions the individual in relation to health services (Fleming and Golding 1997). Within the democratic model, public involvement is linked to maintaining democracy and public accountability within the NHS (Barker et al 1999) and such an approach views the individual as a citizen. Herxheimer and Goodare (1999) assert the term citizen also encompasses everyone, however it does suggest civic responsibility. Such responsibility relates to life decisions and an obligation to participate, with rights relating to service access and equity (Fleming and Golding 1997, Lupton et al 1998). The degree of user control is seen as an important aspect of the model and relates to issues of empowerment (Fleming and Golding 1997). Furthermore, collective action is seen as a way of broadening the participant perspective and experience; however, the approach is criticised for its focus at macro rather than individual level (Lupton et al 1998).

The consumerist model emphasises individual choice with the individual seen as a customer or consumer and where services are adapted to individual needs (Barker et al 1999). Such an approach is based on market relationships (Lupton et al 1998) and service provision is linked to consumer preferences to improve market

competitiveness. The rights of the consumer focus on adequate information, access, choice and redress in relation to a specific service or product (Lupton et al 1998). Public involvement is a management responsibility and equity of provision is not addressed (Fleming and Golding 1997, Lupton et al 1998). However, the consumerist model is limited in relation to a specific act of consumption or service use, with involvement viewed as a series of discrete episodes (Lupton et al 1998). Mechanisms such as audit and quality assurance have a high prominence, but the model sometimes fails to take into account people's ability to act as active consumers (Lupton et al 1998) and the public can be, and are, healthcare suppliers (Rogers et al 1998).

Herxheimer and Goodare (1999) propose that the term 'consumer' has displeased some people, creating an aggressive image, suggesting that health consumers are more likely to demand their rights without exerting their responsibilities, however the authors identify the same universality as 'user' - we are all consumers. Lupton et al (1998) also observe that the NHS has developed more along consumerist than democratic principles and Chapter One identifies its link to health policy within the 1980s and 1990s. Although New Labour policy is more strongly associated with a democratic approach (see DoH 1997) it serves as an example of the lack of clear demarcation between the two models. Indeed, Needham (2003:5) identifies the 'consumeratisation of citizenship' in recent health policy, where consultation promotes individual response rather than collective discussion and service reform is aimed at consumer satisfaction and expanding individual choice.

2.1.3 Lay Members & Non-Executive Directors

Chapter One identifies a long-standing relationship between the NHS and lay member and such individuals are strongly linked to decision-making vehicles such as health panels and committees. This tradition is perpetuated in health policy relating to Primary Care Groups, with lay membership at board level (HSC 1998/139). However, Hogg and Williamson (2001) and Williamson (1999) acknowledge there have been few attempts to define and clarify lay involvement, with the term 'lay' being utilised vaguely and reasons for involvement rarely stated. Definitions that are available tend to identify lay people in negative terms, emphasising their lack of professionalism and specialist knowledge (Brotchie and Wann 1993, Hogg and Williamson 2001).

'Lay people are those who have not gone through the training or socialisation into a particular profession under discussion (such as medicine, nursing, chiropractic) which we refer to as the index profession, Therefore, lay people are assumed to have retained the 'ordinary' norms and values of society' (Hogg and Williamson, 2001: 3)

However, Brotchie and Wann (1993) do offer a more positive description: -

' The lay person is someone who represents the public at large and whose starting point should be the user's or patient's point of view' (Brotchie and Wann, 1993:5)

However, Hogg and Williamson (2001) assert that while lay members, operating on committees, are assumed to be working for patients' interests this may not always be the case and may be aligned to managers or professionals. Within a further definition Brotchie and Wann (1993) also differentiate between the general public and lay representation: -

'The layperson is not just the average person on the street. For whatever reason, he or she is someone who is committed to improving health services and prepared to give time and energy to do so' (Brotchie and Wann 1993:8).

Williamson (1999) also echoes this view, suggesting that lay people often have experiences of the care system and have a patient perspective. Brotchie and Wann (1993) also identify a variety of skills and experiences that lay people bring with such involvement: -

- Personal experience – linked to experience of NHS services and the local community
- Commonsense – commitment, good ideas, a sense of social justice, tendency to challenge and question the planning process.
- Special information – regarding the community.
- Different perspective – general overview in a position to explain policies and services to local people.
- An understanding of where and how services need developing in the community - can identify strengths and weaknesses of services.

- Enabling communication between service users and health service providers – acting as translators, developing a good two-way communication system with local people (Bowen 2000).
- Service provider – may have developed self-help groups, advocacy schemes or alternatives services.

Potential difficulties with lay roles are linked to inadequate representation as such positions can be held by people in positions of authority (Richardson 1989) and a picture of lay members who are 'pillars of the community' emerges (Chambers 2000:5). Furthermore, lay representatives come from largely professional/non-manual and white sections of society (NHS Executive/ISHM and NHS Confederation 1998:10) and this statement is also supported by Giddens (1998). Concern focuses on a reinforcement of the inverse care law (Chambers 2000), as involvement that only benefits well-organised and communicative individuals needs to be questioned (Richardson 1989, Stewart 1999). Lay involvement is also linked to remuneration and Lipman (2003) suggests that this deters disabled people and people on benefits, due to fear of losing such allowances.

By contrast, Lilley (2002:2) maintains there is no confusion regarding the role of non-executive director - simply 'You have no executive powers but a great deal of influence'. A strategic overview is strongly linked to this role (Williamson 1995), with non-executives having to have a financial understanding of the organisation, the wider health economy as well as institutional and national targets (District Audit, 2002). These roles are also linked to strategic direction, performance and risk management as well as overseeing external relationships (District Audit 2002). Lilley (2002) suggests that non-executives can act as a catalyst by creating an enabling environment, which benefits both the organisation and the public. However, the position seems to be one of potential conflict, the role can challenge colleagues and clinicians, however non-executives also have a duty of confidentiality and legal responsibilities, with upward accountability to the Secretary of State (Lilley 2002), rather than the public.

Ashburner and Cairncross (1992) also identify the difficult relationship between issues of secrecy and the expectation of openness and accountability for non-

executive directors. Furthermore, their independent judgement remains contentious (Vevers 1995) and Klein (1998) highlighted their poor performance in relation to the Bristol Royal Infirmary scandal in the 1990s (see Section 4.10). Although the role is linked to giving a community voice to service planning (Williamson 1999), Hogg (1999) asserts that most appointments are not for local knowledge but for professional and managerial expertise. The Labour Research Department (LRD) (1994) investigated the background of chairs and non-executives of all 482 trusts in Great Britain at this time. Their occupational background found that 43% had a business background, with nearly a third being business managers, 7.5% were consultants, 4% owned their own business and over a quarter were company directors. A further 7% were solicitors and accountants - only 7% came from a medical background, which tends to support Hogg's views. Hogg (1999) also identifies that very few of them were women or from minority ethnic communities. Furthermore, Sims (1994) suggests that the skills of non-executives are not always fully utilised, although such roles are linked with heavy time commitments (Lilley 2002).

2.1.4 Groups & Organisations

Historically, specific user or disease-related groups have dominated group involvement (see Section 1.7). Furthermore, this trend continues with recent health policy, which has resulted in the strong emphasis of patient/user rather than citizen involvement (McIver 1998). Difficulties with this approach are linked to the effects of categorisation on the individual as well as representation. Harrison (1999) challenges the legitimacy and representativeness of such groups, as they do not represent wider society or all users and have difficulties with internal feuding, poor management and lack of consultation availability. Harrison (1999:16) continues with the suggestion that the views of such groups can also be outside the 'paradigm of mainstream politics' making it difficult for them to operate in partnership with statutory agencies. However, group action on behalf of individual members, such as patients' rights organisations, can be more effective than an individual approach (Montgomery 1992). Also Kelson (1997) suggests that group members have access to the experiences of a bigger constituency, but emphasises a wide range of groups should participate. There are groups that are not disease/condition related and that continue to be involved, paralleling discussions on NSMs in Chapter One, and include minority ethnic groups, pressure groups and self-help groups (Gurney 1995, Kelson 1997, Entwistle et al

1998). Some are formal groups such as tenants associations, social clubs, others informal such as community centre groups and youth clubs (Kelson 1997).

Voluntary organisations, Community Health Councils and Local Medical Councils are organisations most likely to be linked to involvement within government health policy and such organisations may have generic or specific health interests (Entwistle et al 1998). Voluntary organisations have the advantage of being readily accessible to involvement organisers (Taylor 1995, Chambers 2000). Again the literature identifies that such organisational views are do not necessarily represent the constituents or communities with which they work (Chambers 2000). Researchers such as Taylor (1995) and Lupton et al (1995) have identified the concern of some statutory health organisations regarding the perceived vested interests of such organisations, even a report commissioned by the ACHCEW, acknowledges such difficulties within its own councils (The Commission for Representing the Public Interest in the Health Service, 1999). Perhaps it is concerns over the potential political nature of such organisations (Lupton et al 1995) or lack of democratic credentials (NHS Executive/IHSM and NHS Confederation 1998) that has led to the persistent use of lack of representativeness by the NHS to negate such organisational views and demands (see Section 3.3).

2.1.5 Reaching a Wider Public

The recurrent problems with representation and democratic accountability would suggest that PCGs would need to set up systems to actively seek out and involve beyond the voluntary sector (Chambers 2000). Chambers (2000) goes on to identify a three-pronged approach to developing a more inclusive system in which views should be sought from under-represented and hard to reach groups as well as ordinary people. Both Jakubowska (1999) and Stewart (1999) identify the aspect of democratic injustice that is visible if involvement fails to reach specific communities, particularly, those linked to exclusion. Murray (1999) and Stewart (1999:2) suggest this means special emphasis should given to approaches focusing on groups not normally involved, such communities often have conflicting and more pressing demands (Dobson-Mouawad 2000:160). Smith (1999a) adds to this argument by identifying the lack of agreement on the necessity, appropriateness or methodology of drawing in the wider public.

2.2 Involvement & Related Concepts

As with definitions of 'public', 'involvement' also poses problems and evades simple conceptualisation. Terms such as participation, consultation and involvement are often used interchangeably, with little discussion in relation to their meaning. Other related terms are identified within the literature such as engagement, empowerment and partnership. Gurney (1995) in his own exploration suggests that 'involvement' can be used as a generic term, with consultation and participation more specific aspects of such involvement. They may also represent three different levels at which the public can interface.

Analysis of health policy reveals the predominant use of the terms 'public involvement' (NHS Executive 1992, DoH 1999a) and 'consumer involvement'. Consumerist approaches have already been linked to individual choice and information (see Section 2.1.2) but are also associated with minimum participation (Barker et al 1999:14). Furthermore, Gurney (1995) suggests the term involvement, itself, is less facilitative than participation, as groups or individuals can be either passively or actively involved. Indeed, the term 'involvement' within some NHS/government publications (see Chapter Three) is most strongly aligned to consultation. Consultation provides a 'snap-shot' of present views and is time specific (Dobson-Mouawad 2000:160). Gurney (1995) goes on to suggest that consultation relates to information exchange for a deliberate reason, which should be made clear and presented honestly. However, Chambers (2000:5) observes that 'Many consultations at present involve the most accessible people and simply mirror the power balance that already exists in society'.

The term participation within the literature review reflects a more active, influential process, where the participant is a partner (Gurney 1995). Brownnill and McInvoy (2000:148) identify the varying degrees of decision-making power inherent in both terms, suggesting that participation implies some involvement in decision-making whilst consultation means views can be expressed which may or may not influence decisions, with Kelson (1997) adding that final recommendations are made by professionals. Interestingly, the term 'participation' is conspicuous by its absence in most health policy, lying more forcefully within academic literature (see Klein 1984, Richardson 1989, Gurney 1995, Klein and New 1998, Rhodes and Nocon 1998). One

of the few exceptions is 'In the Public Interest: Developing a Strategy for Public Participation in the NHS' (NHS Executive/IHSM and NHS Confederation 1998). This document does attempt to address the complexity of public involvement and reflects a multi-dimensional and strategic approach that may be due to its collaborative nature (see Appendix One).

Unlike 'participation', partnership has had a recent re-assertion (Doson-Mouawad 2000). Barnes (1999:8) describes a 'new discourse of partnership' within health policy by the late 1990s, with such partnerships encompassing professionals, patients, users and community groups. Partnership is more strongly aligned to the democratic approach (Barker et al 1999:14). Examples of this are seen in 'Patient and Public Involvement in the new NHS' (DoH 1999a), where partnership is seen as 'integral to the work of every part of the NHS' (DoH 1999a:1). Furthermore, it is suggested that such partnerships can provide a catalyst for the development of innovative practice (Brownill and McInvoy, 2000) and key elements to success pertain to equity, common goals and shared decision-making (Coote 1999a), described concisely by Kelson (1997:6): -

'... the views of users and professionals contribute equally to an initiative and users contribute to decision-making, to making recommendations for change and evaluating the effects of implementation'.

However, Dobson-Mouawad (2000) suggests the term is now often abused, Barnes and Warren (1999) criticise both the term involvement and partnership as they both suggest equality, which is often unrealistic. Where 'The New NHS' (DoH 1997) talks of 'partnership' the concept is generally limited to partnership between health and social care organisations, rather than partnership with service users (Rhodes and Nocon 1998:79). Brownill and McInvoy (2000) also identify that there are no requirements to guarantee equal opportunity in relation to representation, which has the potential to allow exclusive practices. Furthermore, the authors describe operational difficulties, as they are time limited and membership can be based on knowledge and networking rather than other democratic criteria. Coulter (1999a) also suggests that partnership has replaced consumerism as a key plank of public policy, a

popular term because 'it evinces a warm glow but also because it emphasises mutual self-help' (Coulter 1999a:719).

Barnes and Warren (1999) identify 'empowerment' as an elusive and contested concept, with lack of an agreed definition, although they suggest it should be viewed as a process. Lupton et al (1995:216) suggests that public involvement in the health service had not typically spanned the full range of different types of involvement and although 'empowerment' is evident in 'Patient and Public Involvement in the new NHS', it is linked only to individuals who have 'expanded roles and control' (DoH 1999a:14). Rhodes and Nocon (1998:79) suggest 'an entrenched resistance to the politics of empowerment and an inability to incorporate an oppositional voice into the planning process'. Themes of empowerment are certainly more readily found in academic literature, particularly, those allied to New Social Movements (see Beresford and Croft 1993, Barnes and Warren 1999, Barnes and Bowl 2001). The term 'engagement' seems an annoying addition to an already confused picture, where utilised (see DoH 1999a, NHS Executive Northern & Yorkshire Region 1999) it is readily interchangeable with 'involvement' and no attempt is made to clarify its use.

2.3 Operationalisation

This section focuses on the principles and challenges regarding the operationalisation of public involvement. Hogg (1999) identifies some of the inherent difficulties with such a process: -

> 'Intellectually it is easy to appreciate the importance of participation and how this will lead to better decision making in the long term. In the short term, however, it is time-consuming, messy, challenging and can delay or destroy the best laid plans' (Hogg, 1999:92)

2.4 Public Involvement Methods

Chambers (2000) asserts that the development of user-sensitive services would require PCGs to incorporate methodologically sound ways of gaining public views. However, the methodological approach to public involvement would also prove a difficult area for PCGs, as there is a wide range of consultation techniques (Hogg 1999) and each has potential strengths and weaknesses as well as an assortment of

resource implications. Gurney (1995) identifies the importance of flexibility within implementation, not only does the purpose of involvement affect the method, such methods may need adaptation to specific groups. Such approaches can include both quantitative and qualitative methodology, Barker et al (1999) highlight a range of approaches: -

BOX 3

Methods of Involving the Public and Service Users

Public meetings

Focus groups

Meetings with carers and user groups

Targeting interested people

Semi-structured interviews

Structured one to one interviews

Self-completed questionnaires

Open surgeries

Information dissemination

Exhibitions

Seminars

Radio/live phone-ins

The press

Other approaches

Rapid appraisal

Community development

Citizens' panels

Citizens' juries

Health panels

Large group processes

Search conference

Open space

Team syntegrity (Barker et al 1999:35 - 72)

This list is not exhaustive. Other documents identify health forums; newsletters; complaints; patient councils; general practice patient groups; public consultation; workshops (NHS Executive Yorkshire and Northern 1999); open days and road shows; information technology (including websites); ballots and deliberative polls (National Consumer Council/Service First Unit 1998). Such diversity of methods

underlines the potential difficulties of appropriate selection and the above list and detailed methodological discussion in Chapter Three also emphasises the high level of skill required to facilitate such approaches.

2.5 Knowledge, Skills & Training

Skills for public involvement are seen as scarce within the NHS, with few personnel having real experience of involvement in healthcare (NHS Executive/ISHM and NHS Confederation 1998, Chambers 2000). Public involvement has not been an integral part of training for health professionals and the literature identified the need to resource skill development throughout the service (NHS Executive/ISHM and NHS Confederation 1998). Although an increased awareness of public involvement issues was noted in GP and nurse training in recent government documents (DoH 1999a), such training would take some time to filter through to practice (NHS Executive/ISHM and NHS Confederation 1998). The impact of inadequate training makes a difficult and challenging activity even more complicated (Jordan et al 1998), often resulting in meaningless consultation (Chambers 2000).

Jakubowska (1999) identified the lack of exploration by health policy and guidance regarding involvement skills within the role of the medical practitioner. The author suggests skills that emphasise co-operation and finding shared solutions, with a willingness to overcome defensiveness are important. Dobson-Mouawad (2000:159) emphasised effective communication - 'Asking the right questions remains easier than listening to the answer. Its remarkable how many organisations still require to learn both skills' Jakubowska (1999) also identified project and time management, the use of plain language, media skills and public awareness. Skills could also be imported or commissioned (NHS Executive/ISHM and NHS Confederation 1998:18) and PCGs had the potential to explore external sources of expertise – social services, voluntary organisations and local government all had an established expertise (Chambers 2000).

Lay representatives would also require skills training and personal development. Such support was seen as essential to prevent involvement becoming exploitative or prohibitive (NHS Executive/IHSM and NHS Confederation 1998) and a potential supporting infrastructure for lay members could have come from voluntary organisations and CHCs (Barker et al 1999). Brotchie and Wann (1993) identified

areas of training within their research, which included community development, communication and representation skills. The authors advocate joint training to facilitate closer collaboration and teambuilding to promote multi disciplinary working. Further suggestions relate to the immediacy of training and that it should reflect local and national changes. Importantly, Brotchie and Wann (1993) identified the style of training, which should recognise the experience and expertise of lay members, trainers should be drawn from the voluntary sector and lay people should be involved in training development.

2.6 Defining Strategy

Amongst the ambiguity associated with public involvement and health policy, two areas were clear: the governing boards of Primary Care Groups would incorporate one lay member, and these new subcommittees were charged with the development and implementation of a public involvement strategy (HSC1998/139). Lay membership has been explored in an earlier section; therefore, the question refocuses on what might constitute a 'public involvement strategy'. Exploration of definitions of strategy lead to further uncertainty, deWit and Meyer (1998) warn against a mistaken belief of a clear definition, as there is no widespread agreement among practitioners, theorists and researchers, therefore making a shared definition of the concept illusive. Joyce (1999) further supports this observation suggesting that characteristically, strategies are linked to fluidity; personnel within public sector organisations cannot always say definitively what strategy is or what their own organisation's strategy is.

2.7 Views on Strategy

Historically, government documentation again lacked detail of how to involve the public strategically (see Section 1.17). Studies such as Taylor (1995) and Jordan et al (1998) identified that most health authorities had no provision for ongoing consultation (see Section 3.7). Further difficulties were identified within voluntary organisations, Barker et al (1999) suggested their expertise focused on how disease was experienced, experience in strategic planning was questionable. Health policy identified inter-agency collaboration within a public involvement strategy (see DoH 1999), however Dobson-Mouawad (2000) findings suggested a lack of strategic co-ordination between departments and agencies often resulting in similar targeted consultation exercises. Smith (1999b) warned that the lack of clear guidelines had the

potential for the involvement arena to be dominated by the most powerful interests. Furthermore, unlike many other aspects of PCG functioning no explicit timescale was given for the development of a strategy and no minimum set standards, leaving the potential for the area to be de-prioritised. Without strategic planning, Lenaghan (1999:11) suggests public involvement mechanisms may continue to grow in quantity but decrease in quality and legitimacy would be lost.

Many authors made general statements regarding strategic planning but again lack the specific detail and examples to assist in its development (see Appendix One). Coote (1999a:14) advocates the need to plan a strategy before selecting methods; the design should take a pragmatic approach, developing on best practice and have built-in evaluation. Brownill and McInvoy (2000) suggest a combination of top-down and bottom-up public involvement initiatives are needed and any strategy should be flexible and open to change. Coote (1999a:14) also advocates a combined approach but places stronger emphasis on bottom-up initiatives; furthermore, the strategy should incorporate clarity of purpose, communication, capacity building and community governance and should take account of all stakeholders groups. Again, long-term strategic effectiveness is dependant on formal structures for continued communication and action in relation to involvement (Jordan et al 1998), as Stewart (1999:2) suggests – '… always respond, interaction is always the key, views should not disappear into a black hole'.

2.8 Planning – Key Elements

As the public involvement strategy was left to the individual discretion of each Primary Care Group, this review focused on the 'process' of involvement and attempts to identify key factors within planning and evaluation of initiatives. Emphasised within all related literature is the importance of clarity of purpose. Lenaghan (1999) warns that lack of such clarity and co-ordination of activity is wasteful of resources and threatens to undermine credibility. Dobson-Mouawad (2000) asserts it is vital as involvement can still be seen as threatening and is often compromised by a lack of objectivity. Coote (1999a:13) also urges the use of a consistent framework to encourage innovation and ensure minimum standards. Some key elements are identified in National Consumer Council/Service First Unit (1998) and, as such, provide an example of a consistent framework relating to planning

initiatives. This has been adapted and utilised to provide areas of discussion (see Figures 1 & 2). In planning and developing initiatives these key areas were identified:

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- Clear objectives
- Audit
- Participants
- Time
- Methods
- Resources
- Cost
- Communication
- Performance Indicators (see Figure 1)
- Formative and Summative Evaluation (see Figure 2)

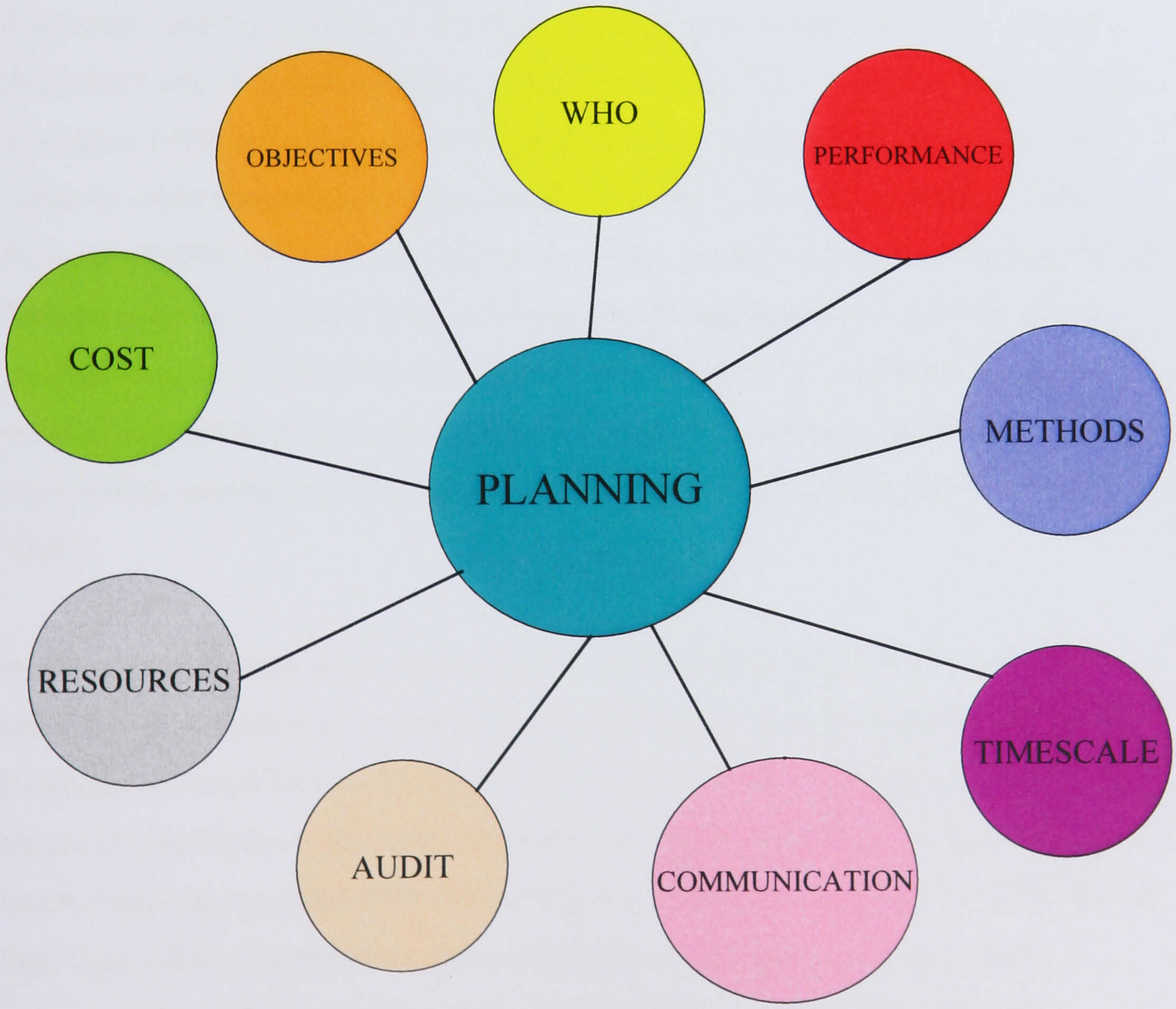

Figure 1: Key Elements of Planning

Clear and realistic **objectives** for each public involvement initiative are essential and can be linked to clarity of purpose. The rationale for involvement should be known, this includes what needs to be found out, who is going to be involved, how it's going to be accomplished and the handling of results (Chambers 2000). The National Consumer Council/Service First Unit (1998) advocates SMART objectives: - specific, measurable, agreed, realistic and time-bound, the objectives should also be linked to the wider planning process, in this case, an overarching public involvement strategy. Such objectives need to be explained and understood by all participants.

Audit is important on two levels, generally primary care organisations need to establish a baseline, which includes a record of activity in relation to public involvement; the audit should also include available resources and information relating to public involvement (DoH 1999a), such information needs to encompass community profiling (Barker et al 1999). Reviewing previous or ongoing projects (National Consumer Council/Service First Unit 1998, NHS Executive Northern and Yorkshire 1999) is seen as crucial to ascertain other agency involvement with the public to avoid unnecessary replication of work and 'consultation fatigue' (NHS Executive/IHSM and NHS Confederation 1998:6, Barker et al 1999, Chambers 2000). Accessing previous research can also help identify appropriate methods as well as highlighting potential pitfalls, furthermore, it can provide an inexpensive route in establishing previous consumer preferences and views without using limited resources e.g. surveys, complaints, suggestions (National Consumer Council/Service First Unit 1998).

It is important to think about who will be involved within the initiative as well as selecting the appropriate method for that particular group of **participants** (National Consumer Council/Service First Unit 1998). Barker et al (1999:22) also suggest that choice of participant is linked to purpose; however there can be specific targets for the level of response required from different groups (National Consumer Council/Service First Unit 1998). The planning phase should ensure adequate and appropriate representation, which includes under-represented groups (National Consumer Council/Service First Unit 1998). Gurney (1995) raises the issue of the **timing** of initiatives; a major problem is consulting when decisions have already been made. Importantly, for involvement not to appear tokenistic public involvement should be

established at much earlier stages in decision-making (Office for Public Management/Patients Association/NHSME 1994). Pragmatically, the length of **time** for consultation is often underestimated, within this time frame there is a need to include feedback of results, which can take longer than the involvement process itself (National Consumer Council/Service First Unit 1998).

Resources - value for money is important in relation to consultation. Staff time and training need to be included in budgets and can be the most expensive element if doing in-house consultation (National Consumer Council/Service First Unit 1998). Analysis of the capacity of providers is therefore important as well as developing set budgets (NHS Executive Yorkshire and Northern 1999). Other **costs** focus on what resources are required, the length of time, personnel and premises. Barker et al (1999:21) highlight the need for a feasibility exercise - to be aware of certain constraints at the beginning. A practical suggestion is the utilisation of existing groups e.g., mother and toddler groups, tenant associations for consultation, also joint agency working can avoid duplication of effort. Commissioning other agencies to undertake initiatives can also be effective (Barker et al 1999:21).

There is no single all encompassing **method** for involving the public (Barnes 1997) and the choice of method should not only match the purpose, but also circumstances and the participants involved (Gurney 1995). National Consumer Council/Service First Unit (1998) suggests that method is also linked to the type of information required. External factors, which impinge on methodology, also need to be taken into account such as cost and budget allocation, timescale and experience available. The choice of methods also relates to the level of involvement (Barker et al 1999), for example public meetings will allow information exchange and public debate but leave little room for active participation.

Integral to the public involvement strategy is the development of an effective **communication** mechanism – not only generally but also for each specific initiative. In relation to gathering, processing and publishing information – Barker et al (1999) asserts the importance in identifying what information is required from an initiative and why. Those who are going to be utilising the information need to be clear about how exactly and when they intend to use the results and should be able to tell

participants why views are being sought as well as when and how they can expect to get feedback on how their views were used and what decisions were made (Barker et al 1999:26). Results cannot be predetermined and can be unpredictable, therefore the focus is on organisational change and responsive structures need to be in place that can deal with information, which may include the analysis of research data (NHS Executive/IHSM and NHS Confederation 1998). Accountability dictates that the organisation must be explicit about the results of that involvement (Barker et al 1999:29) and their utilisation. Dobson-Mouawad (2000) urges that the results of involvement should remain in the public domain. Barker et al (1999:29) suggest it is not only courteous but also pragmatic as feedback helps promote confidence and trust which is the basis of sustainable relationship of any sort.

A communication mechanism should ensure that any initiative is effectively publicised (National Consumer Council/Service First Unit 1998). The initiative should provide all the information about the issues available with no hidden agendas and part of openness and transparency of the process is linked to the reduction of jargon (Chambers 2000), Dobson-Mouawad (2000) also identifies that the use of inappropriate language prevents or deters communities from participating, therefore speech and documentation should be in plain English (Chambers 2000).

The planning of the initiative should also include **performance indicators** or identified success and failure criteria (National Consumer Council/Service First Unit 1998), which can be used as benchmarks for evaluation. The importance of such indicators is also highlighted by Beresford and Croft (1993:202), suggesting that progression on involvement is dependent on 'yardsticks', without such tools there is a likelihood of the same mistakes being repeated and the process remaining vague and confused. Barker et al (1999:20) urge the use of simple measures and furthermore, the use of clear criteria within the planning process could aid the requirement for built-in evaluation (Brownill and McInvoy 2000) and it is in this crucial area that the majority of initiatives fail (McIver 1998).

2.9 Evaluating Initiatives

The need for adequate evaluation procedures was strongly emphasised within associated literature; however, reality revealed few formal evaluations (Gurney 1995,

McIver 1998, Entwistle et al 1998, Dobson-Mouawad 2000). Barker et al (1999:30) suggest that such evaluation is often viewed as unexciting due to unfamiliarity with the concept and its on-going benefits, but can give work a greater credibility. However, evaluation is seen as a vital component and should be included within the initial planning stage (National Consumer Council/Service First Unit 1998). This is reflected in Figure 2, where the same areas identified in planning are used again to evaluate initiatives e.g. were objectives achieved, were the participants representative. Added to this is the area 'future' – as the evaluation should show how results of initiatives link into future developments in public involvement and the overarching strategy.

Figure 2: Key Elements of Evaluation

Barker et al (1999:31) distinguish between two different forms of evaluation – formative and summative. Formative focuses on on-going evaluation or monitoring of the process (Brownill and McInvoy, 2000:151) with the main intention to improve performance and maximise the likelihood of achieving the desired outcomes (Barker

et al 1999). Such evaluation can maintain the quality of involvement, which is often not assessed (Dobson-Mouawad, 2000). On-going evaluation also allows the identification of original or anticipated problems, therefore allowing for them to be dealt with effectively (Barker et al 1999:30).

Summative evaluation focuses on the impact or outcome and should provide evidence of achievements and effects. It involves measuring against a baseline to determine if there has been improvement. This is often done at an end point or at given stages within a project (Barker et al 1999:31) and can be linked to Figure 2. Beresford and Croft (1993:202) advocate the review of both outcomes and process: 'they are indivisible'. Emphasis on what is achieved, but omitting how, leads to the inability to determine the level of involvement and disregarding outcomes limits attention to the requirements of involvement, rather than whether people have really gained anything from it. Such examples show that the critical appraisal of the key planning elements is essential.

2.10 Manuals, Toolkits & Government Guidelines

With evident difficulties relating to strategic development, a variety of manuals, toolkits and government guidelines were analysed to evaluate their potential strategic awareness in aiding PCGs (see Appendix One – Manuals & Toolkits). It was clear in analysing these texts that no one tool would provide a comprehensive guide to developing public involvement within primary care organisations and their local communities, particularly in relation to strategic planning and evaluation; therefore, an eclectic approach to support materials would be required. Beresford and Croft (1993) warn there are limitations to the help that can be expected from detailed guidelines and checklists. Furthermore, those published in 1999 would have been unavailable for shadow PCG boards, which could have potentially restricted the early development of public involvement initiatives. The review of tools also identified the time needed to come to grips with methodological choice and other related issues – the rapid pace of development of PCGs could again potentially impede on the operationalisation of public involvement.

2.11 Commitment, Cultural Change & Power Sharing

Underpinning the successful development of public involvement is an identified need for cultural change and commitment, indeed, a philosophy of public involvement pervading all levels (NHS Executive/IHSM and NHS Confederation 1998). Jones et al (1997) highlight the importance of organisational acceptance of public opinion; this includes legitimatising lay involvement in decision-making (Whitehead and Ray 1999). However, health policy seemed an inconsistent advocate (see Section 1.17, Section 4.4) and lack of government guidance and failure to provide adequate resources left the potential for public involvement to be a low priority. The situation was compounded by professional dominance of the service, the ever-present managerialism and often an unchallenging voluntary sector (see Chapter One). The vested interests of such groups suggested an unwillingness to make such a cultural change (Chambers 2000). This left the potential for a power shift towards the public impossible, with involvement initiatives remaining tokenistic - a public relations exercise rather than an empowering philosophy (Chambers 2000).

2.12 Definitions of Power & Associated Concepts

The need for commitment and cultural change within PCG/Ts and related organisational structures could be viewed as 'obvious'. However, the literature review identified that the importance of an underpinning philosophy regarding public involvement is underplayed by many of the related texts. There is perhaps too strong an emphasis on practical aspects of involvement, often reflecting a tick box, checklist mentality (see Sykes et al 1993, Martin and Evans 1994, Kelson 1997, Health Quality Service 1999, Barker et al 1999, Wilson 1999, NHS Executive Northern and Yorkshire Region 1999, Lilley 1999, Ling 1999). The main barriers to successful involvement – power and domination – tend to be less visible. Having negotiated many obstacles, a systematically well-planned initiative with built-in evaluation could still founder without addressing this crucial area.

As the research study progressed, emerging themes of power and domination from the data analysis became more prominent as did the need to find an explanatory framework in which to discuss specific research findings. This had two major effects on the thesis. Firstly, the study developed to incorporate a fourth phase of data analysis focusing on issues of power and domination in relation to public

involvement. Secondly, the literature review was extended to incorporate an exploration of power and associated concepts; an important aspect of this review was to identify a conceptual framework to support the discussion of study findings (see Chapter Five & Nine). This and the following sections briefly explore the concept of power. Specific emphasis was placed on acknowledged power relationships within the service before returning to the area of evaluation, but this time from a power sharing perspective.

The review found a diversity of interpretations regarding the meaning of power and only briefly highlights a number of frameworks. Stronger emphasis was placed on the work of Foucault as this formed the explanatory framework for results of this research (see Section 9.2). There is a diversity of definitions available for the concept of power. Beetham (1991:45) offered a starting point, identifying power in general terms '… the ability to achieve our purposes', which could also be linked to Wrong's (1979) discussion on capacity, skill or talent. Beetham's (1991:45) definition included an explicit sense of power '… the ability to influence and control the actions of others', which the author suggested was fundamental and a continuing facet in all societies. Lukes (1974:26) definition identified power with significant affecting: -

'The absolutely basic common core to, or primitive notion lying behind all talk of power is the notion that A in some way affects B. But, in applying that primitive (causal) notion to the analysis of social life, something further is needed – namely, the notion that A does so in a non-trivial or significant manner'.

Lukes (1974) goes on to identify ways of affecting; or as Wrong (1979) described it - forms of power, these include coercion, authority, legitimacy, manipulation, persuasion, inducement and influence. Lukes (2005:21) defined coercion as 'securing compliance through the threat of sanction', Wilkinson and Miers (1999) and Torfing (1999) suggest that such power is illegitimate and based and reliant on force. A closely related concept to coercion is authority, however, the defining difference is that the exercise of power is seen as legitimate (Wilkinson and Miers 1999). In other words the legitimate right to act (Torfing 1999) '… when power is accepted as legitimate by those upon whom it is exercised, it is regarded as authority' (Wilkinson and Miers 1999:7). Torfing (1999:164) suggests that subjects voluntarily choose not

to resist this exercise of power, with Handy (1999) highlighting that authority also has some recognised official backing. An exploration of legitimacy, suggests a multi-dimensional quality: -

'…for power to be fully legitimate, three conditions are required; its conformity to established rules; the justifiability of the rules by reference to shared beliefs; the express consent of the subordinate…' (Beetham 1991:15)

Beetham (1991) linked the concept of manipulation to the influence or control of superior knowledge, whereas persuasion required agreement. Inducement was seen as '…the promise to grant or the threat to withhold some resource or service you desire need …' (Beetham 1991:44). Beetham (1991) linked manipulation to power, while persuasion and inducement were seen as influence, with Lukes (2005:21) defining influence as 'Changing B's course of action, without resorting to threats of severe deprivation'. However, Handy (1999) saw power as the enabling process in such behaviour modification.

An exploration of Foucault's definitions of power found the concept more ambiguous (Hindess 1996), with a strong emphasis on power relations (Foucault 1977a:122) and the suggestion that power was everywhere (Allen 2003).

'It seems to me that power is 'always already there', that one is never 'outside' it, that there are no 'margins'…' (Foucault 1977a:141).

2.13 Theoretical Interpretations of Power

Clegg (1989:1) describes theories of power developing on a pair of axes: on one axis is the view of power as contested and relating to causality and agency. Clegg (1989:2) suggests that models within this axis focus on the definition and measurement of power and concentrates on the 'negation of the power of others'. The other axis challenges this viewpoint: here power can be seen in positive terms and not continually contested (Clegg 1989). It can be dispositional, relating to a set of competences, or facilitative or the ability to accomplish goals (Clegg 1989:2). Within this axis power is seldom specifically identified (Clegg 1989).

Hobbes, Locke and Machiavelli are viewed as the forerunners to the modern study of power, focusing not only on the definition but the exercise of power (Westwood 2002). Hobbes linked power to human agency (Hindess 1996), perceiving it in positivist terms as something measurable and observable (Clegg 1989). The theorist gave an account of sovereign power (Hindess 1996) and addressed the problem of order (Westwood 2002). The sovereign monarch was seen as the solution to chaos associated with the state of nature (Torfing 1999) as Hobbes was writing after the English civil war (Clegg 1989). The sovereign was to establish and uphold social orders, via laws, prohibition and punishment (Torfing 1999). The conception of power is one of causation. Subjects would exchange a degree of personal power for social stability in a social contract with the sovereign (Westwood 2002:8). However, Hobbes regarded coercion as the ultimate and the only real form of power (Wrong 1979:45). Locke, like Foucault, identified the idea of a dispersal of powers as a regulatory mechanism in society and was concerned with the idea of laws, rights and responsibilities (Westwood 2002:9).

Theorists such as Dahl, Bachrach and Baratz and Lukes had also developed causal arguments (Clegg 1989). In discussing Dahl's work, power was something held by people rather than organisations, like Hobbes, power was linked to agency and Dahl focused on the measurement of power through responses (Clegg 1989). Clegg (1989:8) identifies this agency '…the power of an A could be measured through the response of a B'. For Dahl power was visible in examples of concrete decision-making, and he took a pluralist approach (Clegg 1989). However, Dahl's model was criticised for being imprecise in relation to some tacit assumptions and its failure to explain the notion of intention (Clegg 1989:8). This was discussed further within Lukes' (1974, 2005) critique of both Dahl's and Bachrach and Baratz's work in his own discussion of a three-dimensional model of power.

In one-dimensional power, the focus was on actual decision outcomes and on concrete observable behaviour, this model assumed that such decisions involve direct conflict linked to a subject of controversy (Lukes 1974:13). Within this scenario, each side was seen to know its own interests and struggled to assert them in a visible and open decision-making process (Lupton et al 1998). Conflict focused on preferences or

conflict of interests; such interests needed to be articulated and observable (Lukes 1974:14). As such, this description incorporates work by Dahl.

The two-dimensional model incorporated both the concepts of power and coercion; the model added that power was often exercised by confining the scope of decision-making to relatively safe issues (Lukes 1974: 17). Hindess (1996) described this as the concealed, covert exclusion of the interests of particular individuals or groups. These non-decisions were themselves (observable) decisions: they did not have to be overt or specific to a given issue or even consciously taken to exclude potential challengers (Lukes 1974, Lukes 2005). However, lack of awareness did not mean that a dominant group would cease from making non-decisions that protected or promoted their dominance; non-decision making also related to suppression or prevention of latent or manifest challenges to the values or interests of the decision-maker (Lukes 1974). Lukes (1974) asserted that it was essential to identify potential issues, which non-decision making prevented from being actualised; such issues were linked to those that would really challenge the resources or authority of those dominating the process (Lukes 1974). Lupton et al (1998) relate this two-dimensional model to the successful monopoly by professionals over the definitions of the issues in public services.

Lukes (1974:22) criticised the other two models as too individualistic and emphasised the 'socially structured and culturally patterned behaviour within groups and practices of institutions, which may indeed be manifested by individuals' inaction'. Lukes (1974) also suggested that there was too strong an emphasis on actual, observable conflict, identifying two types of power that may not involve conflict at all – manipulation and authority: power was not just exercised in situations of conflict. Lukes (1974:24) also identified that by shaping perceptions, cognitions and preferences there was acceptance in the existing order of things, which Hindess (1996) described as the insidious form of power linked to false consciousness.

The model identified many ways in which potential issues were kept out of politics, whether through the operation of social forces and institutional practices or through individuals' decisions. However, Lukes (1974) described a latent conflict, which consists of a contradiction between the interests of those exercising power and the real

interests of those they excluded. Clegg (1989) maintains that the implicit mechanism underlying the third dimension of power was hegemony and elements such as false consciousness and hegemony were also visible in Marxist theories of power. Here, the primary source of class power focused on the private ownership of the means of production, with an emphasis on the control of labour, the mechanism of accumulation, and the role of commodity (Beetham 1991, Westwood 2002). Wilkinson (1999) identified that power was concentrated in the hands of minorities and used by them to further their own interests; power was linked to the control and access to economic resources and coercive in nature. A critique of Marxism came from Poster (1984). He describes a move from the mode of production to the mode of information suggesting that Marxist theory failed to respond to world changes. He identified the predominance of service industries rather than manufacturing, labour now focusing on people acting on information, suggesting that the manipulation of information now tended to characterise human activity.

However, neo-marxist theories have developed, including those from Gramsci, who thought the state was composed of a dominant class developing through compromise and negotiation (Wilkinson 1999). Gramsci described a political and civil society; the former had a monopoly on the use of coercive mechanisms, the civil society worked through the use of institutions. The combination of mechanisms created an acceptance of the general and intellectual dominance of ideas (Wilkinson 1999). Gramsci's view of power emphasised a combination of coercion and consent; consent was gained, as individuals were not aware of their own interests (Hindess 1996). Importantly, his work identified the role of the media in projecting the notion of desire and the investment in consumption, which played a crucial part in global modernities (Westwood 2002).

Weber also identified the importance of the distribution of power and class (Allen 2003) and emphasised the unequal distribution of different kinds of resources (Beetham 1991). Weber suggested that power was evident when one party succeeds despite opposition, this again occurs through coercion, domination and authority (Wilkinson 1999). Power was held at the expense of others and was described as the constant-sum concept of power, those who held power use it to their own ends (Wilkinson 1999). Weber also identified the continuing rise of bureaucratic forms of

power, which stretched out as an immense network through society, producing forms of individuation and alienation (Westwood 2002).

Feminist studies described the negative effects of patriarchy on women and children, rejecting many social theorists due to the invisibility of women (Wilkinson 1999). Such studies include a number of approaches, which provide differing explanations of men's power and the means to address power issues (Wilkinson 1999). Liberal feminists see inequalities derived from unequal access to rights and choice, with solutions located within existing social structures (Wilkinson 1999). Marxist feminism focuses on capitalist relationships as the cause of women's oppression, whereas, radical feminism suggests that the oppression of women and children is the oldest and most extreme force of oppression (Wilkinson 1999). Gender is of central concern, with the desire to control the capacity to reproduce and sexuality seen as the centre of male domination (Wilkinson 1999).

The other axis identified by Clegg (1989) was linked to theorists such as Machiavelli, Parsons and Foucault. Clegg (1989) also suggested that within this axis the conception of power was vague, contingent, strategic and organisational. Machiavelli focused on what power did, with a strong focus on the interpretation of strategies (Clegg 1989). Westwood (2002:8) suggested that Machiavelli provided a 'fascinating account' of power plays and strategies, offering an 'ethnography of power' as it was constituted and re-constituted in the network of relations within a specific, historical context - the palace. Here, power was simply equated with the level of effectiveness of such strategies.

Parsons took a functionalist approach, viewing power as a resource held by individuals and groups, and rejected the constant-sum concept (Wilkinson 1999). In viewing power as a generalised resource possessed by the whole of society, he proposed the variable-sum concept, power increases in society the more society achieves its defined communal ends and visa versa, although this viewpoint has been criticised as naive and uncritical (Wilkinson 1999). The exercise of power by the state was seen as legitimate because government acted in accordance with the wishes of the population; however, it needed to act as an honest broker between competing interests (Wilkinson 1999).

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2.14 The Contribution of Foucault to the Power Debate

Watson (2000:67), along with many authors, viewed Foucault's work as challenging the traditional view of power, with his suggestion that power was fluid and operated in a capillary-like fashion. As discussed in power definitions, Foucault viewed power as being everywhere (Torfing 1999) and not something that could be possessed (Torfing 1999, Watson 2000), importantly it was evident in all social interactions: -

'...power is evident at the point of interaction between individuals. More over power is not held consistently by one or more social groups but emerges in and from their interactions' (Wilkinson 1999:22).

Furthermore, Foucault addressed the important question of what power was doing and how it was organised (Torfing 1999), suggesting it had the potential to be positive, formative and productive (Poster 1984, Clegg 1989, Torfing 1999, Watson 2000, Westwood 2002). Foucault's interrelated concepts of governmentality, discipline, knowledge and discourse proved particularly influential for this study in offering an explanation for the results of policy implementation in relation to public involvement. Within this section the concepts are briefly and generally introduced, detailed discussion is presented in Chapter's Five and Nine.

Foucault gave few direct references to the state in his work, focusing more on governmentality (Watson 2000:71). Dean (1999:11) suggested that the concept of governmentality 'breaks with many of the characteristics assumptions of theories of the state, such as problems of legitimacy, the notion of ideology and the possession and source of power'. The focus moves to the practices of government (Joyce 2001), such practices cover individuals, institutions and the population (Dean 1999:12). Joyce (2001:595) also identified that governmentality links the techniques of discipline and control of individual bodies directly to state policies. Hughes and Griffiths (1999) elaborate on this, discussing the notion of government as the 'conduct of conduct', which means to lead, direct or steer from a distance as well as focusing on individual conduct, which involves attempts to shape behaviour according to a set of norms and for a variety of ends (Dean 1999:10).

Foucault elaborated on his interpretation of discipline through an historical discussion, which compared pre-modern and modern modes of punishment. Pre-modern punishment attacked the criminal body, whilst modern punishments required an inner transformation – the control of the soul (Gutting 2005:81) through discipline. Foucault suggested that the modern approach to discipline aimed to produce 'docile bodies', individuals behaving they way we want and doing what we want (Gutting 2005:82). Docile bodies were produced by three means: hierarchical observation, normalising judgement and a combination of two linked to the examination (Gutting 2005).

Hierarchical observation involved controlling people via observation, Foucault (1977b:200) linked this to Bentham's panopticon, a building associated primarily with penal reform, which incorporated an inner ring of cells with a central observation tower. Any cell could be seen from the front by a supervisor in the central tower, described as 'axial visibility', however the side walls of the cell prevented the prisoner from coming into contact with other inmates – described as 'lateral invisibility' (Foucault 1977b:200). This provided the ideal form of surveillance, within this ring, individuals were totally seen, without ever seeing; in the central tower, one sees everything without ever being seen (Foucault 1977b:202). Those who are knowingly subjected to this field of visibility, assume 'responsibility for the constraints of power' (Foucault 1977b:202). In other words, individuals police their own behaviour under threat of being observed, indeed, just the possibility of observation can control (Gutting 2005). Linked to this discussion is Westwood (2002:19) description of the Foucauldian notion of 'technologies of the self' where individuals are not only disciplined externally, but internally, as individuals observe and punish themselves.

Normalising judgement focused on the judgement of individual actions, not as right or wrong, but through ranking and comparison with others (Gutting 2005). This also meant the individual became the object of punishment not the offence (Miller 1987). Gutting (2005) suggested this was a pervasive means of control from which there is no escape. Classification and ordering became standard techniques of normalisation and the norm became as important as the law in determining social policies (Watson 2000:69). Here, norms defined certain modes of behaviour as 'abnormal' and,

therefore, not acceptable (Gutting 2005). The combination of observation and judgement was inherent in the examination. The examination produced the truth about the subject (Miller 1987), which in turn regulated and control their behaviour accordingly (Miller 1987, Gutting 2005).

Foucault suggested that power and knowledge were closely connected and interlinked, all fields of knowledge were formed within power relations and all knowledge relations formed a field of power (Watson 2000:68). Neither can exist in isolation of one another; knowledge construction also influenced individual behaviour (Wilkinson 1999). Foucault's work focused on two configurations of a power/knowledge nexus - disciplinary power and bio-power, the former is illustrated in practices of discipline (Watson 2000:68), which is discussed within Chapter Nine (see Section 9.2). An example of this power/knowledge nexus is the medical profession that brought new forms of control over the body and the population, gained through the collection of information (Watson 2000:69).

Foucault was also to extend on the concept of discourse, which Watson (2000:70) defined as 'A framework of meanings which are historically produced in a particular culture at a particular time'. Discourses have profound effects and are a major feature of the social field (Poster 1984, Watson 2000). Human subjects are themselves produced within discourses, what is essential is which people and institutions have the power to define the terms of the debate or the way the problems are to be understood (Watson 2000:70). Such discourses can exist simultaneously, some are dominant others can be complementary (Wilkinson 1999:21). Foucault stressed the role of 'discipline' in encouraging submission and 'discourses' in reproducing particular group perceptions of 'truth' (Sanderson 1999).

Joyce (2001:596) identifies that power/knowledge regimes support the rationale of government and goes on to suggest that government power and government itself is as much a product of a discourse as the individuals that are subjectified by it. As discourses change, conceptions of government also change (Joyce 2001). Joyce (2001) goes on to discuss this in terms of health policy, identifying the effect of neo-liberalism, where the view of the NHS changed, with the service seen as a burden to the economy and creating a culture of dependency (Joyce 2001:597).

Westwood (2002) identifies that the concepts of consent or emancipation have no place in Foucault's accounts; however, resistance does. Watson (2000) suggests that Foucault did not view people as victims. Subjects were both the targets of power and its articulation, suggesting there were countless points of conflict and instability and frequent possibilities for tactics and strategies of resistance. Torfing (1999) elaborates on such resistance suggesting that it is not external to power relations it works within and against such relations.

'To say that one can never be 'outside' power does not mean that one is trapped and condemned to defeat no matter what' (Foucault 1977a:141/142).

'There are no relations of power without resistances; the latter are all the more real and effective because they are right at the point where relations of power are exercised'. (Foucault 1977a:142).

2.15 Power & its Relationship to Health Services

Sanderson (1999) has provided an extremely pertinent explanatory framework of power and its relationship to public service organisations: identifying four areas in which power and authority are removed from citizens: - professional power, marketisation and manageralism, organisational practices and culture, and the capacities of citizens. These areas can be directly related to PCG development, as PCGs reflected a new organisational tier within primary care, with the potential to develop an independent culture. However, although PCGs carried devolved powers at Level 2, they remained subcommittees of the Health Authority, with a well-established organisational culture. PCGs also represented the integration of a mixture of professionals and citizens, with managerial personnel holding influential positions at Board level (see HSC 139, 1998).

2.16 Professional Power

Strong and Robinson (1990:41) acknowledge the power of the medical profession: - 'That power has moulded every health care system in the Western industrialised world, regardless of its methods of organisation'. The power of the medical profession manifests itself in a number of ways, with much discussion relating to medical knowledge and professional autonomy (Strong and Robinson 1990). As with

Foucault, Turner (1997) suggests that power and knowledge are inextricably connected with Sanderson (1999:332) identifying that medical knowledge is derived from access to objective, factual knowledge and forms the basis for authority. However, such authority disempowers citizens. Barnes and Warren (1999:13) add to this discussion suggesting that the control of knowledge production is crucial. Practitioners can feel threatened when professional knowledge is being challenged, with fear of loss of power and control and this can lead to defensiveness and closure (Harrison et al 1992). Lay expertise is difficult to acknowledge as it challenges such authority and threatens the existing culture (NHS Executive/IHSM and NHS Confederation, 1998).

Harrison et al (1992) also describe the medical profession as a state-licensed elite. The state uses its legislative authority to prevent non-members of the profession from practising medicine, whilst the profession undertakes to control and discipline its members (Klein 1998). However, public scandals, allied reports and recent health legislation are proving a clear threat to such autonomy (see Section 4.10).

2.17 General Practitioners, Power & PCG/Ts

The development of PCGs represented the first government initiative that meant the compulsory involvement of general practitioners into the NHS corporate structure and their establishment were seen as a potential challenge (Meads 1999). Potential assaults on the GP power base were quickly identified within the medical press, with many identifying a threat to clinical freedom, challenges to independent contractor status (Chisholm 1998, Campbell and Proctor 1999, Davies 1999, Warden 1999) and back door regulation (Neal 1999). Beecham (1999a) identified the need to raise morale and restore professional control.

However, a combination of unchallenging health policy and the mobilisation of general practice would ensure that their power base remained intact. The White Paper (DoH 1997) was seen to give a central role to GPs in the construction of the new NHS (Beecham 1998b). Meads (1999) asserted that 'general practice will not easily pass away as the 'Number One' unit of primary care in England too much capital was invested in it'. The issue of influence was seen as important in regards to the development of PCGs (Proctor and Campbell 1999). The BMA's General

Practitioners Committee (GPC) issued guidance regarding their role on PCG boards called 'Maximizing Your Influence' (Beecham 1998a). This guidance advocated a unified view, taking up a Board majority, appointing a GP chairperson and leading on the development of the PCGs constitution (Beecham 1998a).

The strong emphasis on control is reflected in the rhetoric of the time: 'General practitioners will run the boards of PCGs' (Groves 1999:747), also '… doctors who run PCGs…' (Roberts 2000). Willis (1999), providing a nursing perspective identified PCGs as a chance for shaping and prioritising services, but highlighted concerns over the dominance of GPs, whereas professions allied to medicine had no right of representation. This position was cemented by Alan Milburn's (health secretary) decision to allow choice of GP majority and chairship by the medical profession in June 1999 (Gilley and Majeed 1999), allowing GPs almost exclusive influence (Smith 2000). Even though Williamson (1999), in discussing lay partnerships advocated that the number of lay and medical members should be equal. Rhodes and Nocon (1998:79) commented that Government attempts to secure professional goodwill had led to the regaining of such authority, which seemed to have unintentionally opened the door to a return to professional paternalism.

Medical dominance fuelled concerns regarding the level of disruption to local service delivery, with energy focused on structures and power struggles (Behan and Loft 1999). Furthermore, dominance of GPs potentially meant health improvement being defined in relation to medical interventions (Behan and Loft 1999, Fisher and Gillam 1999). Power struggles were also evident within the nursing profession, with Willis (1999) voicing concerns regarding competing with both GP and social service dominance in existing structures.

The idea of trust status was welcomed by a majority of GPs (Beecham 1999b), affording greater flexibility (Davies 1999) and freedom from health authority control (Audit Commission 2000). Concerns mirrored those of PCGs – the loss of influence and control in the new structure (Neal 1999, Roland 1999). It was clear that the profession would not vote for arrangements that would diminish power (Starey and Marchment 1999). Much discussion focused on the lay-dominated board (Neal 1999) and the professionally dominated executive committee, with fears over the potential

reduction of influence at board level (Davies 1999, Wall 1999, Audit Commission 2000). However, Neal (1999) suggested this concern was misplaced: GPs would not be marginalised, as they would have two representatives on the board. Few health authority boards reflected this and such representation was not reciprocated within executive committee membership, as Neal (1999;22) stated '...the real influence will reside in an effective executive'.

2.18 Marketisation & Managerialism

Sanderson (1999) also identified the concepts of marketisation and managerialism as disempowering and the concepts are discussed extensively in Chapter One (see Section 1.9, Section 1.10, Section 1.11, Section 1.12). Indeed, Harrison and Mort (1998) suggest that consumers were given increased power only over issues that held little professional interest, with consumer choice affecting managerial staff and less powerful professions, with the more powerful able to preserve their autonomy. Managerialism continued to be evident within New Labour policy, with the preoccupation with efficiency and performance management visible within New Labour policy (see DoH 1997). Sanderson (1999), in his discussion, identified the continuing focus on defined objectives, expressed in quantitative terms. Such objectives were to be seen as the prerogative of experts and reflected the values of dominant stakeholders - the primary aim to control rather than democratise and this required no participation of citizens (Sanderson 1999:334).

2.19 Organisational Practices & Culture – Primary Care Context

Harrison and Mort (1998:68) identified that particular modes of social co-ordination also implied particular sources of legitimacy. In discussing the quasi-market structure within the NHS, we see a different mode of social co-ordination, moving from total hierarchy to a network (Harrison and Mort 1998). The authors suggest that the network produced implicit bargains and worked for the benefits of insiders, although difficult to legitimise – extending this network to the public was an obvious means of seeking to enhance legitimacy, whilst the control of such participation remained in the management domain (Harrison and Mort 1998). The formation of PCG/Ts also showed potential for networking and alliances, indeed, the emphasis on collaboration was evident in health policy and formed one of the Government's six main principles in relation to the new NHS (DoH 1997).

However, Peterson (1997) warned that alliances consisting of different levels of government, private bodies, non-government organisations and community groups would create multi-levelled and multi-organisational networks of surveillance and regulatory practice. Furthermore, Sanderson (2000) and Brownill and McInvoy (2000) both identify the potential difficulties with networking, as management tend to involve those who have an established relationship with the organisation, acting as an exclusive practice to hard to reach groups. In addition, historically health authorities have not been bound to the decisions of public consultation; outcomes can instead be used for internal political purposes (Harrison and Mort 1998).

Christie (2000) identified the importance of organisational development in relation to successful participation; however, Sanderson (1999) identifies some of the realities. Organisations may be charged with undertaking consultation but not given the resources, support or power of discretion from senior managers, which is needed for effective implementation (Sanderson 1999). Frontline workers can also be given contradictory objectives, constrained by specific policies, priorities and procedures (Barnes and Warren 1999, Sanderson 1999). Timescales for planning and decision-making in the organisation could also form a barrier to participation, failing to allow user groups sufficient time to consult their consistencies. Frustratingly, these problems can be seen within the development and functioning of PCGs, no ring fenced budget, no additional funding and not allied to a senior management position (see Chapter Four and Ten).

2.20 Citizen Capacity

A number of barriers exist that make involvement extremely difficult for certain individuals and groups with prejudice and negative stereotyping continuing as covert barriers (Sanderson 1999). Christie (2000) identified that difficult to reach groups are often also socially-stigmatised, observing that different opinion groups have differential access to power and influence, as stated access is often by the affluent strata of society (Giddens 1998). Furthermore, people with learning disabilities, mental health and physical impairments face problems of labelling and prejudice and do not conform to the established model of involvement, which is structured around people without such disabilities (Sanderson 1999).

Strongly reflected in discussions of citizen capacity is the concept of representativeness, which is discussed throughout the thesis. Sanderson (1999) extends the argument by describing the concept as a double-edged sword, acting in a number of ways to disempower the public. Experts often define the need for participants to be representative of those for whom they speak, however critical viewpoints could still be dismissed as unrepresentative (Sanderson 1999). Such difficulties are exemplified in the NHS Executive/IHSM and NHS Confederation report 'In the Public Interest' (1998:19), which identifies the 'quasi-representative nature' of many lay members, highlighting that non-executive membership of the NHS boards is drawn from local people who have no specific democratic credentials. Such difficulties are strongly linked to the concept of legitimacy; unelected individuals or groups, such as CHCs, were criticised for their lack of democratic credentials and therefore their legitimacy to speak is challenged.

Authors such as Beresford and Croft (1993) and Lupton et al (1995) identify that involvement does not usually equate to influence, particularly in relation to organisational decision-making. This is also reflected in participants' scepticism regarding the impact of their involvement (McIver 1998). Individuals, groups, organisations and communities are, therefore, left with the difficult decision of whether to opt for internal influence or outside lobbying. Richardson (1989) also discusses this dilemma, suggesting that involvement can be seen as a clever con, co-opting individuals into the system and potentially reducing the influence of the consumer population. Smith (1999b) supports this, suggesting that public participation can be utilised to stop the public blocking difficult decisions. It is, therefore, important to assess the level of power sharing or power distribution in involvement initiatives.

2.21 Evaluating the Power Balance in Involvement

This final section returns briefly to the notion of evaluation. What is clear from the discussions on power is that part of the evaluation must focus on the level of empowerment associated with strategies and initiatives. There are a number of frameworks, which have the potential to evaluate power sharing; several are identified in this text. Authors can describe involvement as a continuum, whilst other theorists see it as a ladder. Each framework shows the level of inherent power.

For example, Fleming and Golding (1997) identify the following continuum: -

- Providing information
- Gathering users' views
- Consulting users
- Engaging users
- Including users in decision making process
- Delegating control to users

Wright (1999) suggests a similar model and both identify control by users as important.

Supporting user-led initiatives (Most Power)

Helping user groups by providing training, use of premises, business planning advice and acting as champions inside NHS systems.

Work Together

Working with users who want to help the NHS organisation change, in working with parties, project groups, through evaluation, audit and through users as trainers.

Gather Ideas/consult

Using people's expertise as service users to get new ideas about how to do things. Asking people what they think about plans and proposals.

Give Information (Least Power)

Letting people know what is happening. Giving people enough information to enable them to make informed choices (Wright 1999:60).

Barker et al (1999:14) identify three levels of involvement: -

- Minimum participation – geared mainly towards informing, where people are passive receivers of information.
- Participation – geared to participation of the public as consumers in order to receive information and advice from them.
- Partnership – geared to involvement of the public as partners in order to service or empower them where they have expanded roles and control.

In evaluating health service initiatives within Chapters One & Three, the majority of efforts focus on consultation and information giving and, therefore, provide the least power and a minimum level of involvement. Arnstein (1969), cited in Lupton et al (1998), works within a democratic viewpoint and the model stands out as one of the most influential works in relation to power relationships (see Figure 3). Within this

framework there are a range of different types or levels of participation, again they are presented in a form a 'ladder' in relation to who holds the power and the extent of influence involved.

Citizen control	Degrees of citizen power
Delegated power	
Partnership	
.....	
Placation	Degrees of tokenism
Consultation	
Informing	
.....	
Therapy	Non-participation
Manipulation	

Figure 3: Arnstein's Ladder of Citizen Participation cited in Lupton et al (1998:47)

Therapy and manipulation are seen as participation exercises designed to ensure a 'feel good' factor, giving people a voice as a way of making them feel involved, improving their skills in working together or ensuring their compliance (Lupton et al 1998). This level of participation involves little commitment to or possibilities for real influence, examples given are: - groups run in residential establishments, consumer surveys undertaken as public relation exercises, statutory consultation exercises where real decisions have already been taken (Lupton et al 1998).

Information giving is interpreted as tokenism, with the power to define what information will be given remaining in the hands of the instigators of the exercises (Lupton et al 1998). Consultation seeks to listen to the views of participants before decisions are made; a move up the ladder can be facilitated if accompanied by a commitment to act on the views expressed (Lupton et al 1998). Placation is offering a very limited role for public participation within a much wider area of decision-making (Lupton et al 1998).

Within partnership power is delegated. Citizen control identifies forms of participatory activity in which the public has greater power, where there is commitment to ongoing activity and where a developmental approach exists to integrate the views of the participants fully within the wider decision-making process (Lupton et al 1998). Examples of citizen control are user-led projects, community initiatives, locally run services (Lupton et al 1998). This model has been criticised for a failure to consider the role of professional expertise within the participation process, however, Arnstein (1969) cited in Lupton et al (1998) interprets all professional input as disempowering in all circumstances.

Summary

Chapter Two has provided a valuable exploration of definitions of public involvement. Definitions of 'public' offer different perceptions on the role, rights and responsibilities of participants. Different interpretations of 'involvement' determine the level of joint decision-making and power sharing. The conceptual exploration also aided an evaluation of previous public involvement initiatives that are presented in the following chapter. The discussion also identified the importance of determining the purpose of involvement and highlights essential elements related to its strategic deployment. An important exercise as Chapter Four reveals that the public involvement strategy for PCGs (DoH 1997, HSC 139 1998) was to remain ambiguous.

The chapter also identified the importance of cultural change and commitment within primary care organisations for public involvement to succeed. However, the crucial issue of power and power sharing was poorly addressed in much of the associated literature. This could be due to the complexity of 'power' as a concept, which offers diverse definitions and multiple theoretical interpretations. This fact and the identified power relationships within new primary care organisations suggested that addressing power issues would be a complex and difficult endeavour. However, an exploration of Foucault's work provided a valuable insight into the impact of governmentality and discipline in shaping behaviour. The review concludes that the level of power sharing should be addressed as part of the planning and implementation process of public involvement initiatives. As such, the following chapter also incorporates an assessment of power sharing as part of its review of research evidence. Furthermore, a

theoretical interpretation of power was utilised to explain primary care organisational responses to central policy directives in Chapter Nine.

CHAPTER THREE

Research Evidence

Introduction

Chapter Three forms an appraisal of research evidence, literature reviews and reports in evaluating the effectiveness of public involvement initiatives. The review identifies two fundamental difficulties. Firstly, many initiatives had not been formally documented leaving such evidence inaccessible (Beresford and Croft 1993). Secondly and paradoxically, the review also provided evidence of documented public involvement initiatives stretching back over a number of decades. However it was a confused picture, presentation of data was widespread, sporadic and unsystematic, incorporating political, social and health-related disciplines. In consideration of the diversity of public involvement initiatives available for evaluation, an in-depth review across such a wide field would have been beyond the scope of this work, consequently the review for this thesis focused on specific criteria.

Emphasis was placed on research evidence from primary care, community initiatives and citizen/consumer involvement as these areas were seen as the most pertinent to the thesis. McIver (1998) identified a predominant research focus on user involvement, with fewer instances of citizen involvement. Harrison (1999) however observed that public funding of the NHS suggests that all citizens, whether or not current users, should be able to participate. The review therefore did not include initiatives related to secondary care and patient participation, with the exception of patient participation groups due to their potential to be regarded as a local element within a public involvement strategy (Brown 1999). Research literature and reports mainly originated from the 1980s and 1990s: with specific emphasis on health related issues and the majority of initiatives were based in the United Kingdom. Notable exceptions to these criteria was the analysis of the Peckham Pioneer Health Centre and the Oregon Experiment, as both provided essential and timeless lessons on the successes and failures of public involvement.

3.1 Citizens' Juries, Panels, Deliberative Polls & Consensus Conferencing

3.1.1 Citizens' Juries

Juries debuted in the United Kingdom (UK) in 1994 via a collaborative effort from the Institute for Public Policy Research (IPPR) and the Institute of Local Government Studies (McIver 1998:5) with the IPPR sponsoring a pilot series of five juries, addressing health policy questions in 1996 (Coote and Lenaghan 1997). Three pilots were also conducted in 1997 commissioned by health authorities and sponsored by the King's Fund, with another six pilots commissioned by local authorities (Coote and Lenaghan 1997, McIver 1998). Such juries have addressed a diversity of topics (Smith and Wales 1997) and this analysis focused on a range of pilots as well as pilot evaluations by Delap (1997), Coote and Lenaghan (1997) and McIver (1998).

The main characteristics of British Juries are as follows: -

BOX 4
Characteristics of British Citizens' Juries

- Citizens' juries are an attempt to involve the public in decision making which affects them
- They involve 12 to 16 members of the public recruited to be broadly representative of their community
- They are brought together for four days with professional moderators and are asked to address an important question about policy or planning
- Jurors are fully briefed on the question by means of written evidence and from information from witnesses. They scrutinise the evidence, cross examine the witnesses, and deliberate on their decisions in small and large groups
- A jury is normally commissioned by a body, which has the power to act on its recommendations. While these recommendations are not binding, the commissioning body is expected to publicise the findings and respond to them within a set time (Delap 1997:6)

The advantages of citizens' juries have been linked to service development as well as addressing democratic difficulties within the NHS (Smith and Wales 1997, Elizabeth 1999). Juries were seen as a vehicle to broaden policy evaluation (McIver 1998, Price 2000) and encourage 'active citizenship' (Elizabeth 1998:17). As a deliberative process, jurors are given adequate time and information to make informed decisions about complex health issues (Lenaghan et al 1996, McIver 1998).

Analysis of research evidence identified that juries were used to address a diversity of health issues: -

BOX 5
Identified Health Issues for Citizens' Juries

- GP shortages
- Palliative care
- Priority setting
- Genetic testing
- Young people and drugs
- Purchasing services from osteopaths and chiropractors

Examples of jury questions include: - 'What are the priorities for improving palliative care in Walsall?' (Delap 1997:23), 'What conditions should be fulfilled before genetic testing for people susceptible to common diseases becomes available on the NHS?' (Dunkerley and Glasner 1998:184). Multi-agency steering groups (including providers, interested parties and user/CHC representatives) were usually utilised to refine questions and determine the jury agenda (Dunkerley and Glasner 1998, Elizabeth 1998, McIver 1998). However, Price (2000) maintains that the form of such questions can act in an exclusionary way as the jury is asked to discuss and evaluate the potential consequences of aspects of health care policy. However, he maintains people more naturally speak about actions and rights (Price 2000). Similar difficulties were also identified by Lenaghan et al (1996) with the Cambridge and Huntingdon Health Authority pilot, where the jury was given a broad set of questions concerning decision-making in priority setting, observations suggested that initially jurors found such a broad question difficult to answer. The researchers concluded that the broader the question, the longer is needed to deliberate as well as affecting the ability to give concrete proposals.

Most pilots reflected the process described by Delap (1997) (see Box 4) although some diversification was seen at Buckinghamshire Health Authority (investigating purchasing services), which also included an electronic citizens' jury (Delap 1997). The electronic citizens' jury was an attempt to complement its face-to-face counterpart and extend impact (Delap 1997). It was made available to Buckinghamshire residents via a website with access points set up across the county, registration allowing access to discussion and voting rights. Although, McIver (1998)

describes that the electronic jury had some success in reaching a wider public, Delap (1997:24) identified that, of 411 visitors to the website, only 36 voted.

Many of the juries were not only provided with briefing notes but also heard testimonials from a number of expert witnesses (Prosser 1996:9). For example, the Sunderland Health Authority jury examined suggestions to counteract general practitioner shortages i.e., the use of salaried GPs, developing the role of nurse practitioners and/or the role of community pharmacists. The six-day deliberation included evidence given by nurse practitioners, general practitioners and community pharmacists (Gulland 1997). Similarly, the London Borough Council jury on young people and drugs interviewed police representatives, drug users, youth workers and council specialists (Thompson 1997).

However, Dunkerley and Glasner (1998) reporting on the first Welsh Citizens' jury, which addressed genetic testing, found that jurors did not have relevant background briefings or written information which would have supported the deliberation.

Dunkerley and Glasner (1998) described a complex system, where witnesses were able to observe proceedings from within a jury room, with jurors hearing evidence from 14 witnesses within four days. The researchers also identified attempts to manipulate the jury, this focused on the way in which witnesses were introduced. Medical witnesses were introduced by their titles, whilst non-scientific witnesses (often with similar standing) were referred to by name only (Dunkerley and Glasner 1998). A pharmaceutical company also sponsored the process itself, raising issues of vested interest.

This above example suggested the necessity for moderation (Coote and Lenaghan 1997). Research evidence identified the importance of moderators, removing bias from the process and supporting group dynamics. For example, Lenaghan et al (1996) identified that the more articulate, confident, experienced and better-educated jurors tended to dominate discussions. The jury was therefore split into two smaller groups and gender issues were also addressed (Lenaghan et al 1996). Moderators were also seen as important acting as chair: in trying to ensure punctuality, full participation and witnesses kept to their brief (Lenaghan et al 1996).

Research evidence suggested that such juries were able to provide sponsors with a range of recommendations in addressing the required health issues and within the allocated time limit (Delap 1997, Gulland 1997, Elizabeth 1998). Furthermore, jurors' recommendations were viewed as practical and in-line with government policy (McIver 1998:6). Such realistic and practical views are evident within the research review e.g., Sunderland Health Authority jury in deliberating GP shortages were able to offer a package of measures and the health authority staged a public meeting to consider the options (Gulland 1997). Although there were some paternalistic views expressed by Gulland (1997) focusing on jurors' abilities to understand primary care issues within a limited time span. However, the Lewisham jury members also presented realistic expectations, with a strong emphasis on drugs education, see below: -

BOX 6

Jury Recommendations – Lewisham

- Teachers should have more drugs education and more resources
- Lewisham should set up an 'elite' drugs education squad
- That the illegality of drugs should be included in the message about their risks and that the message should concentrate on minimising risks (Thompson 1997:22)

The Welsh jury, deliberating genetic testing, made 28 recommendations, grouped under the following headings: -

BOX 7

Jury Recommendations - Wales

- Ensuring Equity of Access to Genetic Services
- Achieving the Right Balance of Funding
- Improving Genetics in Primary Care
- Ensuring Adequate Counselling for All
- Maintaining the Regulatory Framework
- Expanding Professional and Public Education
- Keeping the Public Involved (Dunkerley and Glasner 1998:185)

Jurors also demonstrated the ability to suggest other sources of funding to enable recommendations to be addressed (McIver 1998). The ability to make clear, realistic and often innovative recommendations tends to undermine arguments that members of the public are unable to understand the complex health issues as they not only understand issues but are able to address them (Coote and Lenaghan 1997, McIver 1998). However, Price (2000) complained that such pilot reports did not reveal how decisions were made. Evidence from McIver (1998) tends to discredit this view,

reports by independent observers not only included information regarding juror recruitment, independency of facilitators, type of witness evidence etc but also the way in which jurors reached decisions.

Coote and Lenaghan (1997) highlight the potential limitations of such juries, as their verdicts were not binding. However health authorities, within the pilots, were required to publicise the jury findings and respond in a set time, either by following recommendations or explaining publicly why it was not possible. However, within the reports and research analysed little evidence is given on the impact of recommendations made by juries. Delap (1997) identified that Walsall Health Authority, in relation to palliative care services did take action on some recommendations incorporating some into their overall strategy but these are not identified. A pharmaceutical company sponsored the Welsh Jury on genetic testing but there was no clear commitment to the adoption of recommendations (Dunkerley and Glasner 1998). More encouragingly, Thompson (1997) identified that the London Borough Council was putting jury proposals regarding young people and drugs into action and a further report by the New Economics Foundation (1997) found that the council had also set up a four year borough wide Community Drugs Education Project.

Elizabeth (1998) in evaluating three Kings Fund pilots, identified variation in sponsor responses. Although recommendations were taken to board level by participating health authorities, implementation of recommendations were hampered by a lack of monitoring and long-term follow up. Within the IPPR pilots, McIver (1998) found that the health authority sponsors had developed built-in formal mechanisms to receive, respond to and implement recommendations. Jury recommendations were received at public meetings and a progress review was again given at a public meeting six months later. McIver (1998) also identified that working groups were incorporated to ensure implementation of recommendations, however no specific changes were identified within her evaluation. Similar findings were identified in Milewa's (1997) research, which focused on the relationship between a system of mental health forums and the local health authority focusing on the subject of priorities in mental health provision. Milewa (1997) found that the forums had little impact on decisions

regarding local provision, with lay decisions measured against other organisational necessities.

More positively, research evidence suggested that participation in citizens' juries had facilitated personal development as well as organisational learning (McIver 1998). Jurors were enthusiastic regarding the experience and the majority would take part in another initiative (Coote and Lenaghan 1997). Elizabeth (1999) found that jurors reported the gaining of self-confidence, Coote and Lenaghan (1997) and McIver (1998) identified that jury service had facilitated meeting and working with different people. Furthermore, jurors gained knowledge of the NHS (Coote and Lenaghan 1997) and enjoyed taking part in decision-making (McIver 1998). Although jurors were cynical about whether public involvement made any difference, they thought they had a right to be involved and felt a sense of ownership (Coote and Lenaghan 1997). Furthermore, participation had encouraged active citizenship, with jurors getting involved in conference presentations and joint working groups (Coote and Lenaghan 1997), importantly, the jurors reflected a citizen perspective, with the ability to think on behalf of others (McIver 1998).

A number of difficulties were identified within the literature and research regarding the use of citizens' juries such as representation, time and cost. Dunkerley and Glasner's (1998:183) evaluation of the Welsh jury identified that participants were randomly chosen to 'broadly represent the Welsh population in terms of major socio-economic variables'. However, the research criticised its lack of multi-cultural perspective, with no philosophers, lawyers, health economists and young people. The small groups linked with juries were again questioned in their ability to represent the wider community (Prosser 1996, Gulland 1997). Thomas (1999) mirrored Richardson's (1989) concerns over the impact on health inequalities if minority groups' views were not heard. McIver (1998) also identified problems with non-elected jurors and the lack of a statistically representative sample.

Resource issues were also highlighted, for organisations the method required a long planning phase (Thompson 1997, McIver 1998). Paradoxically, Coote and Lenaghan

(1997) identified juror's complaints over the limited time available to absorb information. IPPR pilots cost £16,000 plus staff time (McIver 1998) and Elizabeth (1998) suggested that juries needed to justify their cost. Juries were also criticised as a way of freeing health authorities from charges of being dictatorial (Price 2000), or gaining public approval for rationing services (Bower 1996) or justifying moral decisions (Price 2000). Dunkerley and Glasner (1998) certainly highlighted their potential to be manipulated. However, the greatest weakness identified within the research is the lack of adequate evidence in relation to the implementation of recommendations. Elizabeth's (1998) evaluation acknowledged that health authorities remained the final judges to how much influence the jury recommendations had in relation to other stakeholders. Such observations highlight Chapter Two discussions on commitment and organisational change and this research evidence suggests resistance to power sharing on the part of participating health authorities.

3.1.2 Citizens' Panels/Standing Panels

Lomas (1997) advocated the use of panels, rather than juries as selected citizens were representative and brought together routinely to arrive at consensus views. Harrison and Mort's (1998) research also focused on health panels, which included citizens' juries within a UK-wide data collection in 1996. This included 40 health authorities and CHCs running or planning to run health panels, with the research aim to categorise types of involvement. Harrison and Mort (1998) classified findings using two independent dimensions – deliberation/non-deliberative, informed/uninformed and identified four main types of consultation exercises reflected in the two-by-two matrix (see Figure 4).

The matrix provided different answers to one of the research questions posed, 'which people?' Harrison (1999) identified a series of implicit assumptions underpinning these different consultation mechanisms, which were rarely discussed explicitly.

	Informed	Uninformed
Deliberated	Citizens' Juries User Consultation panels	Focus groups
Non-deliberated	Questionnaire survey with written information	Opinion surveys of standing panels/one-off questionnaires

Figure 4: Approaches to Public Consultation (Jordan et al 1998:1669)

One version of 'the people' was informed and deliberated; the implicit object was to produce a consultation response which proxies what the public would say with the same knowledge and discussion opportunities (Harrison and Mort 1998). However, this deliberated/informed mechanism tended to be relatively expensive and harder to defend in terms of representativeness (Harrison 1999). The polar opposite (which included the majority) were of people who are isolated and uninformed, the objective, was to obtain a statistically representative account of public opinion as it 'really is'. The researchers identified that this type of consultation (e.g., questionnaire) was cheaper than juries and face-to-face panels (Harrison and Mort 1998). A third construction of people focused on ignorance with the need to engage in deliberation, usually through focus groups, in order to allow opinion to emerge (Harrison and Mort 1998). Finally there is a version of 'people' whose isolated non-deliberated responses were validated by virtue of their having received briefing information on the topic of consultation (Harrison and Mort 1998).

The research found an increasing participation movement within the NHS, labelling this as a 'consultation industry' (Harrison and Mort 1998:64). Many health authorities were actively marketing their consultation methods within the NHS but very few clinicians were involved in public participation work, this remaining within the domain of press/public relations or communications officers. Harrison and Mort (1998:64) labelled such individuals as 'participation entrepreneurs' acting as

persuaders for public involvement work within their own organisations. They also found evidence that the method of consultation defined and limited the sort of questions that were put to health panels (Harrison and Mort 1998). Furthermore, there were few instances of panels themselves being asked to set the agenda and there was a sense of frustration among some participation entrepreneurs that difficult issues were not often tackled (Harrison and Mort 1998). As with reports on citizen juries, the research showed a lack of firm advanced commitment to abide with panels' findings, the focus being on advice not recommendations. Harrison and Mort (1998) concluded that panels could have an important function in informing, educating, influencing even improving accountability, but not so far in changing, determining or shaping policy.

3.1.3 Deliberative Polls

Deliberative polls were developed by Professor James Fishkin as an attempt to move beyond traditional polling methods (Delap 1997). Park et al (1999) identified the difficulties with vehicles such as Gallup, describing such polls a fundamentally flawed as most members of the public did not have sufficiently well informed opinions. Deliberative polls were utilised to bridge the gap between actual and well informed public opinion, focusing on what the public would think, had it a greater opportunity to consider the question at hand (Fishkin 1995:162). As such the method reflects a view of the public as informed and deliberated if utilising Harrison and Mort's (1998) matrix. Park et al (1999) elaborated on this definition suggesting deliberative polls fulfilled three roles: descriptive, by firstly plotting general public opinion, predictive, identifying how opinions may change over time and prescriptive, revealing what a better-informed public would think.

The technique included a random sample of the electorate, with 250 to 600 participants (Delap 1997) – the sample was a statistical representation of the total population (Pickard 1998). Participant experience mirrored that of citizens' juries; briefing materials were available with small group discussions with the opportunity to question opposing experts and politicians (Fishkin 1995). Following 2 to 4 days

deliberation, participants would take part in a poll and the resulting survey offered a representation of the considered public judgments (Fishkin 1995).

Nine polls have been held in Britain (Delap 1997). The first poll relating to the health service took place in 1998, focusing on health rationing (Park et al 1999). The poll was timely, with interest in the issue of rationing health services emerging in the mid 1990s. Hope et al (1998) highlighted government apathy in relation to rationing, with political parties unwilling to acknowledge its inevitability (Smith 1996). Smith (1996) suggested that health authorities were explicitly excluding treatments and Maynard (1996) asserted that the Department of Health condoned such practices by encouraging local discretion. The result was a NHS with unequal access to care.

The deliberative poll on health rationing commenced with a household survey interview, followed by a self-completion questionnaire and informants were then offered to take part in a televised weekend (Park et al 1999). This weekend engaged 228 informants in the health rationing debate, focus groups comprising of approximately 15 randomly assigned individuals were formed and the process also included expert and political plenary sessions. At the end of the weekend another self-completion questionnaire was given to informants to measure '… the direction, volume and distribution of change in attitudes' (Park et al 1999:2). Specific findings were: -

BOX 8

Findings from Deliberative Poll

- A substantial minority favoured increased government spending on the NHS
- Little support for explicit rationing criteria
- Recognition that some forms of implicit rationing already takes place
- Deep suspicion regarding rationing and questioning of whether criteria would improve the situation
- Fear that decisions on priorities set by government or NHS administrators were misplaced
- The decision should be left as far as possible to individual doctors to make inconsistent treatment decisions unfettered by rules or legislation (Park et al 1999:3)

Although other UK deliberative polls had been associated with a substantial attitude change, the poll on health rationing did not reveal a similar result (Park et al 1999). The researchers put forward a number of explanations - the event could have failed to get issues across or public attitudes to the NHS were more robust than towards other issues covered by deliberative polls. Results certainly suggested a resistance on the part of the public to become directly involved in rationing health care.

However, research by Bradley et al (1999) focusing on an exploration of citizens' attitudes towards the health strategy set out in 'The Health of the Nation' (1992) found a greater willingness to contribute. Their study was conducted in four general practices and a secondary school in southwest England and included 24 focus groups (n=173). Twenty three groups were drawn from lists of NHS registered patients, stratified by the Health of the Nation target categories and one group was drawn from 13 to 15 year-old girls at a mixed secondary school. The focus groups generated views and arguments in relation to the Health of the Nation strategy, producing 26 specific ideas for strategic development across five key areas. These ideas were congruent with action plans generated by a national expert groups convened by the DoH, whose role was to review the strategy's progress (Bradley et al 1999). The researchers reported that the focus groups moved beyond experts' proposals, with further practical ideas to achieve national targets. Again this supports findings from citizen juries, participants are able to produce innovative ideas and make realistic recommendations on health issues, in this case, comparable with experts.

3.1.4 Consensus Development Conferences

Stocking et al (1991) discussed a series of eight consensus development conferences (CDC's) in the UK, sponsored by the Kings Fund from 1984 to 1990, with the CDC's initiated to promote change in health policy and practice. The conference development conference (CDC) focused on a medical condition or procedure and assessed related scientific evidence leading to the generation of a statement, which summarised the '…current state of knowledge about best practice' (Stocking et al 1991:7).

BOX 9

Consensus Development Conferences – Focus Assessment of Medical Technology

- Coronary bypass grafting
- Breast cancer treatment
- Stroke treatment
- Genetic screening
- Cholesterol screening
- Intensive care
- Colorectal cancer
- The Role of asylum (Stocking 1991:8)

The UK conferences reflected a number of similarities with juries and deliberative polls and combined elements from town and scientific meetings as well as the judicial process (Stocking et al 1991). As with juries, events were held over three days with statements presented at a public meeting. Preliminary statements were formed of specific questions and drafted by a panel compromising of a mixture of professionals and lay people. There were presentations of scientific evidence with audience participation. Stocking et al (1991) identified that audience numbers ranged from 200 to 300 people through the eight CDC's. Again the audience was a mixture of professionals and lay people. Following the conference the statement was modified and then disseminated via the medical/popular press and direct mailing to interested parties (Stocking et al 1991).

An evaluation of the implementation and impact of CDC's again produced similar findings to citizens' juries. Much of the success was linked to process with Stocking et al (1991) discussing the level of public involvement within public meetings. Time was given to enable the audience to ask questions of speakers and to submit written points to the panel, later conferences incorporated open sessions for greater audience participation. Furthermore, professional practitioners found the presentation of evidence to a lay audience a rewarding experience, again, the audience's ability to grasp issues was highlighted as well as professional misinterpretation of patient need

and experience (Stocking et al 1991). However, familiar problems were also identified.

Stocking et al (1991) identified the vagueness of the implementation of recommendations generated by consensus statements. The authors suggested some examples of local policy/practice changes and increased general awareness, however, '…there was little to suggest that any one statement had immediately been accepted by all relevant parties, or had led to a strategy of implementation on a wide scale' (Stocking 1991:32). The authors also identified problems with accessing a wider general public, a national newspaper had ran a feature on one of the conferences increasing public interest, however, the media was mostly interested in the outcome rather than publicising events (Stocking 1991:12). Dissemination did not reach an adequate number of practising clinicians and the public and the report was disappointed that CDCs were not more widely accepted and supported (Stocking et al 1991).

3.2 The Oregon Experiment

The Oregon experiment in the United States was a significant attempt at priority setting carried out in 1988 (Gurney 1995). The Oregon state identified a budgetary shortfall and was unable to provide all-inclusive health care for clients living below the poverty line (Templeton 2002). Within the experiment there was an attempt to rank services in relation to their relative benefits to the whole population and public involvement was utilised in this prioritisation. Methods mirrored discussions on deliberative approaches in Section 3.1 above and incorporated community meetings, public hearings and telephone survey (Gurney 1995). The ranking of services was the responsibility of a Health Service Commission, a small group consisting of professionals and lay people, although with a provider majority (Gurney 1995). The ranking, informed by professional and public opinion, focused on cost and quality of life issues (Gurney 1995).

However, a number of methodological problems were inherent within the experiment in relation to the type and level of public involvement. 47 community meetings were

held, with small and large group discussions on priority ranking (Gurney 1995:42). Those services falling within the lowest rankings would not be state funded. These included the treatment of end stage AIDS, liver transplants for alcoholics, care of extreme premature babies, back pain and food allergies (Templeton 2002), suggesting potential prejudicial attitudes to perceived self inflicted conditions. Bowling (1996) conducting the first research into health service priorities, based on a random sample of the British population, also found ethical issues in the way treatments were ranked. Results from an interview survey of 2005 adults, found that the public prioritised treatments specifically for younger rather than older people as well as some public support for people with self inflicted conditions receiving lower priority for care.

In contrast, Hay (1996) conducting a small study utilising focus groups, found investment in services for mental illness and elderly people were a higher priority than cancer and high technology surgery. Hay (1996) suggested prioritisation related directly to employed methodology and criticised Bowling's use of interviews, asserting that focus groups facilitated greater discussion. However, the Oregon Experiment did use discussion groups (which tends to undermine Hay's assertions), although it is unclear within the experiment the level of information given to group participants and therefore it is uncertain how deliberative the process was.

Dolan et al (1999) described research with 60 randomly chosen patients meeting in 10 groups taken from two urban general practices. The patients participated in two meetings, two weeks apart. Half the respondents initially wanted to give lower priority to smokers, drinkers and drug users, but after discussion no longer wished to discriminate (48% changed their minds). Dolan et al (1999) again suggested that surveys were of doubtful value. The research suggested systematically different views were given if there was an opportunity to discuss. Such observations highlight the difference between instinctive views and considered responses (Hanratty and Lawlor 1999) and may suggest that a number of meetings were required within the Oregon Experiment.

The Oregon Experiment also included a telephone survey, which involved 1001 residents. However, Gurney (1995) described this as highly complex, with

respondents having to scale health symptoms and functional impairments. Twelve public meetings were also held in Oregon, involving 45 testimonials given by healthcare consumers as part of the experiment. Again, problems with representation at the meetings emerged, attendees were mainly white, from a higher income bracket and college educated, (Gurney 1995) and 69% were health care providers (Lomas 1997). Furthermore, Lomas (1997), in a study of health care consultations, identified that participants in both a volunteer group and a randomly selected group were more likely to be employed in health care than general members of the public.

The complexity of the survey and questionable representativeness at meetings suggested a lack of expertise and skill in planning the public involvement initiatives, which included engaging the wider public and marginalised groups. Finally, the information from public consultation, within the Oregon Experiment, was only utilised in the final stage of ranking - after the list had already been compiled (Gurney 1995), raising issues regarding the timing of the involvement and how public data is utilised. The value of this consultation is highly debated, Gurney (1995) arguing that it was tokenistic, a way of validating decisions, however, Hogg (1999:97) described the experiment as an innovative example of consultation, suggesting that despite its difficulties, it was an determined attempt to address complex issues and as such provided some useful lessons. The experiment also raised questions related to shared responsibility and the public's role in 'tough rationing choices' (Lomas 1997: 103). The ranking and provision of services can be seen as pushing difficult decision-making into the public arena when responsibility for an effective financial strategy for service provision lies with health service management (Lomas 1997).

3.3 Research findings from Community Health Councils

Chapter One has already identified a number of difficulties linked to CHCs, particularly issues of representation and accountability. Early research provided a detailed profile of members and their developing relationship with health authority planning processes. Klein and Lewis (1976) conducted a national survey of CHC members (64.7% response rate) and the profile reflected a predominantly middle-class and middle aged membership, with nearly four times as many members drawn from the professional classes, with 51% working full-time (Klein and Lewis 1976). The

survey also identified members associated with other special care groups such as mental health groups, older adults and children and maternity (Klein and Lewis 1976). CHC members were also more likely to be a member of a health or social care organisation than those focusing on civic activities and 42% had a present or previous occupation in health/social care and other public services (Klein and Lewis 1976). Such findings tend to compromise the ability of members to offer completely objective and unbiased perspective.

In assessing the role of the CHC, two thirds of members saw this role as representing the community interest in the health service, the other third saw the organisation as acting as a channel between the NHS and the community emphasising a meditating role (Klein and Lewis 1976). Importantly, the continuing theme of low public awareness and interest in CHCs was also identified (Klein and Lewis 1976:117). Lewis (1976:2) also conducted four case studies, finding the role of councils vague and ambiguous, this research also supported the profile data by identifying the professionalism of CHC members and highlighted the potential conflict of interest.

Research by Lewis (1976), Dunford (1977) and Weller (1977) all identified issues associated with information, this related to difficulties in receiving information from various NHS agencies. However, Dunford (1977), found that CHCs welcomed opportunities to be involved in the planning process, at the time of this research, this was seen most effectively at district level, although such involvement was not associated with voting rights. Effectiveness was also linked to early involvement in the process (Dunford 1977). However, Weller (1977) in a smaller study, which included interviews with NHS administrators and CHC secretaries, identified conflicting perceptions of the ability of councils to participate in planning stages. A major area of disagreement was the level of information given to CHCs, with difficulties identified surrounding professional autonomy and confidentiality (Weller 1977). This was an area also identified by Mullen et al (1982), along with concerns of the politicisation of health and the legitimacy of CHC's. Councils, themselves, found capacity difficulties in dealing and responding to service information (Weller 1977), with concerns of the potential loss of independence associated with involvement in service planning (Mullen et al 1982).

An interesting phenomenon within the research review was the number of research projects, particularly surveys that were either initiated or supported by the ACHCEW itself, perhaps, linked to the need to continue to justify their existence and contribution. Farrell and Adams (1981) conducted such a survey of 228 CHC's (83% response rate), the findings supported Dunford (1977) conclusions, with councils feeling overwhelmed by the amount of information they were receiving as well as the level of understanding required for giving effective advice and bureaucratic demands. The councils' involvement in consultation regarding service changes left little time for involvement in local activities and again the research identified a limited relationship with primary care (Farrell and Adams 1981).

Within this period the role of CHC's was developing, which included opinion surveys, complaints and alternative proposals for change or service closure. However, councils were still experiencing staffing difficulties and unevenly distributed resources (Farrell and Adams 1981). Hogg' s research (1986) also identified seven areas of involvement, which were re-stated by Ham (1992) within a CHC member handbook. Hogg (1987) provided evidence of good practice covering a variety of areas: - visits, surveys, service information, advocacy, and staff development. However, Hogg and Winkler's (1989) report identified continuing difficulties with general practice, within an inadequate framework for user involvement. Other problematic areas related to the lack of CHC rights within general practice, limited contact with Family Health Service Authorities (FHSA) and time pressures (Hogg and Winkler 1989).

Another concern identified by Hogg and Winkler (1989) was the increasing marginalisation of CHCs, with health authorities taking on the role of champions of the people (see Chapter One). Problems with marginalisation and effectiveness were to continue through the 1990s. Another survey by ACHCEW (1990) focused on CHC relations with NHS authorities and identified difficulties with active involvement in authority meetings, sometimes even speaking proved difficult. More worryingly were concerns regarding the exclusion of CHC's from private meetings, with tactics of using private seminars to discuss strategic development, whilst reducing the number of public meetings (ACHCEW 1990).

Problems with public awareness continued, Buckland et al (1994) interviewed 400 members of the public as part of a street survey. The study found the majority of informants were unaware of independent sources of information about local health provision, with only 2% identifying CHCs. Nearly a quarter of informants did not know how to make a complaint (those who had made a complaint went to its source), only 1 in 10 informants were aware of the work of CHC's (Buckland et al 1994). Research by O'Kelly and Thompson (1993) also provided an inconclusive survey regarding CHC complaints, with informants identifying there was no way to complain about the CHC itself when councils handled complaints ineffectively. However, 63% of informants did find the CHC extremely useful, valuing its independence and assertiveness (O'Kelly and Thompson 1993).

A national survey conduct by Lupton et al (1995) elicited major differences between CHCs relative to their relationship with local healthcare purchasers and providers. Lupton et al (1995) also describe the development of research following on from the national survey, taking the form of case study analysis of five health authorities and five CHCs. Selection of CHCs were via 'cluster analysis' from original survey data and were representative of a range of councils nationally (Lupton et al 1995). CHCs were defined in terms of the level of involvement within health authority (HA) decision-making and their role perception focusing on oppositional or collaborative perspectives (Lupton et al 1995:219). The analysis generated a five-fold typology (Buckland 1992).

BOX 10
CHC Typology

- **HA Partners** – CHCs working closely with their local HA and involved in formal and informal decision-making processes; concerned with individual consumer complaints, but not always taking the side of the consumer
- **Consumer Advocates** – CHCs actively working for consumer rights and on the consumers' side; working informally with their HA, although limited involvement in formal decision-making processes
- **Patients Friend** – CHCs representing consumers on an individual rather than collective level; limited involvement in formal decision-making processes
- **Independent Arbiters** – CHCs acting as referee between the consumer and the HA, taking the side of neither; limited involvement in formal HA decision-making processes
- **Independent Challengers** – CHCs actively working for collective consumer rights; not working closely with HA and largely excluded from formal or informal decision-making processes (Lupton et al 1995:220)

As can be seen from Box 10, the researchers utilise two continua – involvement and independence, confrontational and collaboration to develop five categories of CHCs. Health authorities were more likely to value CHCs who were prepared to work with them over difficult issues rather than stand outside and criticise. Researchers found that the level of opposition affected the extent to which CHCs were involved in HA decision-making. The relationship between involvement and opposition was complex, the actively oppositional Consumer Advocate worked quite closely with its HA, however the more neutral Independent Arbiter was largely excluded from such decision-making (Lupton et al 1995:221).

CHCs who appeared less well informed about current issues and debates were seen to lack credibility. Consumer Advocate was tolerated because of its knowledge of consumer issues and its contact with the local community. Lupton et al (1995) identified two reasons for seeking a collaborative relationship with CHCs on the part of health authorities. CHCs were seen as a source of public views/concerns but also to minimise public criticism of their decisions. Opposition was more likely to be accepted if it was channelled via internal mechanisms. HA partner was more likely to be trusted with confidential material, the other four case studies did not develop this level of trust (Lupton et al 1995).

The overall view of health authorities in relation to the level of influence exerted by CHCs was limited, holding a peripheral position in relation to major policy decisions. Independent Councils were seen at the least influential; Lupton et al (1995) also identified a passive influence, were CHCs played a role of scrutiniser or acted as a catalyst for more rapid decision-making. Councils working more closely with health authorities were not accorded any formal rights and their involvement was dependent on their 'goodwill', highlighted in earlier research. Furthermore, close involvement by the HA partner was seen at the expense of a degree of independence, incidents where CHCs were not working very closely with their health authorities had a greater tendency to be bypassed, with authorities directly consulting with the public particularly with representatives from voluntary organisations.

Lupton et al (1995:223) suggested that public involvement seemed to be part of a more general 'legitimation strategy' on the part of HAs. The extent of involvement

appeared to have little influence on the outcome of decision-making such influence being focused on marginal issues such as quality assurance. Most CHCs felt that their role was to legitimise decisions that had already been taken, influence was linked to 'matters of detail rather than strategic direction' (Lupton et al 1995:223). Influence for independent CHCs came in the form of opposing formal proposals service closures with varying levels of success.

However, Hogg's report (1996) identified the continuing erosion of the rights of CHC's with restrictions on visiting NHS, general practice and private sector facilities, as well as lack of speaking rights at HA meetings and no rights to attend Trust board meetings. Again, there were continuing examples of ACHCEW surveys identifying areas of good practice (ACHCEW 1997). However, the effectiveness of CHC's remained questionable, Rolfe et al (1999) found widespread variability in performance with a lack of direction and focus. Similarly, Dabbs (1998) reviewed issues of effectiveness with research that combined literature review with CHC consultation – again the variability of councils in terms of efficiency and effectiveness was highlighted as well as their lack of focus. However, his discussion of future CHC models would be eclipsed by recommendations for the councils' abolition (see Section 4.11).

3.4 Patient Participation Groups & General Practice Initiatives

Brown (1994) cited in Adams (1995) identified that there had been few opportunities for community participation in primary health care in the UK. Such participation, where it did exist, were mostly top-down initiatives, where involvement was seen as an 'end' rather than a 'means' (Asthana 1994 cited in Adams 1995). Brown (1999) conducted a comprehensive literature review focusing on the development and impact of patient participation groups (PPGs) within general practice. The review identified PPG function and activities, distribution, GP attitudes and representation issues. Richardson and Bray (1987) cited in Brown (1999) conducted a comprehensive study of PPGs involving a national survey (93% response rate) combined with six case studies.

Although many PPGs struggled with their primary purpose (Brown 1999), the review identified three types of PPG activity: -

BOX 11
PPG Activities

- **Voluntary services to patients** – such as transport and prescriptions collection schemes, visiting and befriending schemes, running a crèche at the practice. Fundraising and organising of social events
- **Feedback about the practice organisation** – such as the use of suggestion boxes, surveys and interviews with patients, open meetings and mechanisms for dealing with complaints.
- **Health Education** – such as organisation of lectures, discussion groups, encouraging the formation of self-help groups, campaigning on local health issues (Richardson and Bray 1987 cited in Brown 1999:172)

Pietroni and Chase (1993) cited in Brown (1999) found that the voluntary aspect of PPGs was most successful, with established initiatives often continuing to thrive even after the groups demise. The slow development of PPGs was also highlighted. By 1980 there were 30 known groups, a national survey in 1986 identified 63 groups (Richardson and Bray 1987 cited by Brown 1999), with Pritchard (1993) cited in Brown (1999) estimated this number had risen to 300 by the early 1990s.

Richardson and Bray (1987) cited in Brown (1999) identified that only a minority of PPGs had been going for more than five years. Furthermore, PPGs were unevenly distributed around the country, 71% were situated in rural or small town practices whilst less than 10% were associated with inner city areas (Richardson and Bray 1987 cited in Brown 1999). Hogg (1999) suggested that urban practices are associated with a transient patient population and smaller practices and may not have the capacity to develop such groups. PPGs were associated with larger group practices; with over 50% in practices with more than five partners, only 16% were associated with small practices of 1 or 2 GPs (Richardson and Bray 1987 cited in Brown 1999).

Early work by Pritchard (1981) cited in Brown (1999) identified unrepresentative membership and this trend was to continue, research by Hutton and Robbin (1985) cited in Brown (1999) utilising a structured questionnaire, also found an unrepresentative population sample involved in PPGs. Research by Richardson and Bray (1987) cited in Brown (1999) found the majority of PPGs were open to patients

of the practice/health centre; only 3% were explicitly open to all residents of an area. Similar to CHCs, Hogg (1999:95/96) and Lupton et al (1998) identified that participants were most likely to be older, female and from a higher social class. Furthermore, research by Taylor and Lupton (1995) identified the difficulties of a group that had not been mandated by the wider patient group. Again, like CHCs, PPGs suffered from low levels of awareness (Richardson and Bray (1987) cited in Brown (1999), Agass et al (1991) cited in Brown (1999)). Problems with widening participation and lack of decision-making capabilities may go some way to explain the lack of interest, which was highlighted as the main cause of PPG failure (Mann 1985 cited in Brown 1999).

Research suggested that professionals responded to such groups positively. Wood and Metcalfe (1980) cited in Brown (1999) interviewed 25 GPs, 10 with experience of PPGs and 15 without such experience, their qualitative study found favourably responses from GPs with group experience. Doctors without such experience were likely to have mistaken ideas about the purpose and functioning of such groups and were much more sceptical about their value. Similarly, Brown (1994) cited in Adams (1995) interviewed 23 GPs and 38 community nurses in a Northern England inner city district. The research identified limited direct experience of PPGs nonetheless the majority attitude was favourable to such groups, although concerns were raised regarding the practicality of PPGs without additional resources.

In 78% of cases such groups were initiated by the GP (Richardson and Bray 1987 cited in Brown 1999). Motivation for group initiation included extending the means of helping patients and establishing feedback mechanisms (Richardson and Bray 1987 cited in Brown 1999). However, Hogg (1999) maintained that the intrinsic weakness of PPGs was a dependency on GP commitment, with close dependency in relation to information and guidance (Taylor and Lupton 1995). Taylor and Lupton (1995) went on to identify the difficulties experienced by those participating in developing a strong independent voice and in expressing opinions, particularly if they were contradictory.

The effectiveness of groups revealed a mixture of process and outcomes such as changing services, fundraising, voluntary work, changing relationships and the enjoyment of taking part (Richardson and Bray (1987) cited in Brown (1999)).

However, the review identified different perspectives on the level of decision-making by the groups (Richardson and Bray 1987 cited in Brown 1999, Pietroni and Chase 1993 cited in Brown 1999). Brown (1999) echoed the Lupton et al (1995) assessment of CHC influence stating that such groups had had only a superficial effect on direct decision-making or influence on NHS policy and the costs of such groups remained unclear. Brown (1999) also suggested that it remained uncertain how PPGs related to other public involvement methods/ institutions within their localities, which included PCGs.

Brown (2001) went on to explore organisational values in general practice. The results from a multiple case study design, involving four general practice organisations, identified the impact of organisational values on public involvement (Brown 2001). The findings suggested that an orientation to a narrow medical model and to general practice as a business were linked with a low estimation of involvement; an orientation to teamwork and to a broader social role was more harmonious with the development of involvement (Brown 2001). Brown (2001) revealed power as a crucial issue with continuing medical dominance in establishing values and the nature of involvement.

Furthermore, an evaluation of commissioning and Personal Medical Services (PMS) pilots provided little evidence of involvement. Few commissioning groups involved patients or the public in planning services or appeared to know how to go about involvement (Chambers 2000). This was also the finding of Hine and Backmann (1997) in discussing 20 initiatives relating to locality commissioning, identifying that it was the locality itself that influenced professional decision-making rather than social services, CHCs and voluntary organisations. The first wave of PMS pilots focused on a number of vulnerable and disadvantaged groups such as 'the elderly, the severely mentally ill, the homeless, ethnic minority groups, drug addicts/those at high risk of HIV infection, refugees, and other disadvantages groups' (Leese et al 1999:32). However, a review of the report's analysis of the pilots' key objectives found user involvement/participation was a low priority, organisational structure taking precedent (Leese et al 1999:31). Reports, research findings and comments from reviewed total purchasing pilots (Butler and Roland 1998, Goodwin et al 1998, Fisher et al 1999) made no mention of patient or public involvement at all.

3.5 Peckham Pioneer Health Centre

The Peckham Experiment swims against the tide of characteristically short-lived and ad hoc community initiatives. This was a long-term public involvement project, the main phase spanning 15 years. The experiment had two distinct stages; the first, beginning in 1926, focused on establishing a 'family club' in a small house in Peckham, London to study the nature of health (Scott-Samuel 1990). The project identified that health was linked to personal growth, after planning and fundraising (Scott-Samuel 1990) a second phase running from 1935 to 1950 was initiated in a purpose built health centre (Pepper 1993). The centre was open plan and combined access to leisure facilities and medical personnel. The facility was a precursor to the recent development of healthy living centres (Hogg 1999) and advocated in New Labour's health strategy and again targeted deprived areas (Iliffe 1999).

A number of salient features set the centre apart from the prevailing emphasis on disease and cure, the focus was on health cultivation and developing a social environment (Scott-Samuel 1990): -

BOX 12

Salient Features of the Peckham Experiment

- The study of health rather than disease
- A holistic approach
- Social Club
- Family Membership
- Health checkups and family consultations
- Limited membership and easy access
- Non-directional self-help
- Non-competitiveness, emphasis on taking part
- Open plan building
- Nutrition – organic food
- Open discussion – equal partnership (Scott-Samuel 1990:11/12)

There was a deliberate lack of organised social and physical activities described as a 'hands off' management style (Pepper 1993:14). Authoritarian approaches were seen as inhibiting self-initiative, responsible action and freedom of choice (Pepper 1993).

Project staff, therefore, played a supportive role in facilitating members' expressed needs (Scott-Samuel 1990:15). Literature relating to the project emphasised a humanistic perspective exalting human potential, but the project's ethos has also been viewed as social engineering where experts enlightened participants (Iliffe 1999).

Health checks and the doctor-patient relationship also broke with medical tradition, with the sharing of health information and knowledge, strongly advocated in initiatives such the Patient Partnership Strategy (NHS Executive 1996). Such information formed part of an overall strategy of involvement relating to health choices (Scott-Samuel 1990:28). The centre also emphasised the importance of social support and networking (Scott-Samuel 1990).

BOX 13

Key Achievements – Peckham Pioneer Health Centre

- Improved psychological & physical well being
- Greater permanence of recovery
- Increased vitality within members
- Excellent child development and growth
- Integrated community
- Intergenerational mixing
- Increase availability of information (Pepper 1993:15)

Within the fifteen-year experiment a number of achievements are identified (see Box 13). The key features and achievements of the experiment reflect a number of innovative but potentially challenging practices in relation to healthcare and health professionals. The emphasis on inherent potential, self-initiative and freedom of choice linked with an unobtrusive management style, contrast starkly with the prevailing paternalistic views of the 1940s (Le Grand 2000, Klein 1984) and as such were challenging to established authority. Achievements are recognisably qualitative in nature, it is perhaps unsurprising that an experiment standing in opposition to the prevailing medical model and quantitative models of needs assessment (Sanderson 1999:332) was seen with a high level of scepticism (Stallibrass 1989).

The centre closed in 1950, even though 'in social and research terms it was doing extremely well' (Pepper 1993:14). A number of reasons are linked to its termination: the centre's philosophy and focus on health promotion contrasted to the narrow definitions of health prevalent within mainstream medicine and little was seen as relevant to theory and practice (Stallibrass 1989). Closure was also linked to financial difficulties, government indifference and the growing expectations of the new National Health Service (Hogg 1999). It was, perhaps, also a victim of being ahead of its time, as many of themes pioneered within the centre such as holism, partnership, information sharing and social support, were to re-emerge in mainstream medicine and policy directives decades later.

Many arguments relating to the present day relevance of the project sit within a post modernist perspective. Stallibrass (1989:192) describes a scene of increased questioning of scientific knowledge and a developing lack of acceptance of the legitimacy of intellectual, political and religious leaders, asserting that there has been a refocusing on self instinct and judgement, elements supported and cultivated within the project. Stallibrass (1989) concludes that with overstretched, over worked medical personnel, health cultivation should be self-determined. Furthermore, Pepper (1993) maintains that the set of principles regarding health cultivation continue to provide information on practice and have been utilised in a number of settings such as industrial training schemes, employee development and organisational restructuring. However, Iliffe (1999:15) maintains the project has been romanticised, asserting that healthy living centres such as the pioneer centre are 'a social necessity in an unjust society'.

However, the Peckham Experiment clearly reflected many of the fundamental principles embodied in public involvement. The project demonstrated a commitment to involvement as well as cultural change (Chambers 2000) with evidence of active citizenship, where self-initiative and responsibility was strongly advocated, combined with an identifiable subsidiary role for professionals and managers. This not only reflects elements of other community involvement initiatives but also current government policy rhetoric on the individual's responsibilities and obligations in relation to health cultivation (see DoH 1998a 'Our Healthier Nation').

3.6 Rapid Appraisal

This method for rapidly identifying and defining issues (Dale et al 1996) has been used to prioritise and address health needs (Clasper and Pugh 1995), understand service use and identify implications for service planning and development (Dale et al 1996, Murray 1999). It is flexible, adaptable and can incorporate multiple methods (Cresswell 1992). Murray (1999), a strong advocate of rapid appraisal, also suggests it fosters closer links with community leaders; importantly the method facilitates involvement without substantial personnel or cost outlay (Hamilton and Watts 1994). The research studies reviewed reveal that the technique is often linked to a clearly demarcated community, often residing in deprived areas. Furthermore, it has the capacity to incorporate a number of data collection tools within its implementation.

Murray et al (1994) assert the importance of triangulation within such appraisal exercises. Within their own research of residents of a Scottish housing estate, the researchers used documentary analysis, interviews and observation to increase scientific rigour and validity to the findings (Murray et al 1994:698). Needs assessment included interviews with 45 key informants (including voluntary services, church, police, community development, local authority, health service personnel). Although the sample reflected a predominance of service providers, the research also included a representative sample of 17 local residents (Murray et al 1994:698) as well as four group discussions. Information from data collection methods was categorised utilising an 'information pyramid', which was utilised to identify community's problems and priorities (see Box 14).

BOX 14

Identified Problems & Priorities

- Health Policy
- Educational services
- Health services
- Social services
- Physical environment
- Socio-economic environment
- Disease and disability
- Community composition
- Community organization and structure
- Community capacity (Murray 1999: 441)

Dale et al (1996) utilised interviews, questionnaires, focus groups and community development to identify difficulties with an 'out of hours' service, located in a diverse multi-ethnic, socially deprived inner city district. However, the research project reflected a strong focus on provider views, 8 out of the 13 data collection methods identified were targeted at GPs, service managers and community nurses (Dale et al 1996:1207). The five public involvement methods identified were questionnaires, community development work, CHC consultation and meeting/conference presentation. As with 'Local Voices' (see Section 3.7.1) there was a strong emphasis on information giving/exchange rather than direct participation. Furthermore, community development remained unspecified. Researchers also identified differing response rates from questionnaires; the largest response coming from GPs and nurses (71%) and (54%) respectively, responses from voluntary organisations around (19%). There was also uncertainty regarding how many voluntary/community groups were active in the locality suggesting inadequate profiling of the area.

The researchers argued that the public involvement methods helped valid findings (Dale et al 1996:1208), however little specific details are given regarding these methods and the description of the conference again suggests a dominance of providers. Furthermore, Murray (1999) identifies the impractical use of rapid appraisal within large and diverse settings – Dale et al (1996) described exactly this, a

diverse inner city district of over 700,000 people. This should have meant subdividing the area into natural communities, although, it can be argued that the rapid appraisal focused on one specific service.

Cresswell's (1992:14) work centred on a working class community with high levels of unemployment with an eventual focus on single parents and children within the area. Unlike Murray et al (1994) and Dale et al (1996), Cresswell (1992) does not utilise a triangulated methodology. Emphasis was placed on 54 interviews with local residents, which included 2 group interviews with school children with follow up interviews with 18 residents. The interview period took place over a 34 day period. Interview questions included perceptions of the area, health and social problems and existing service provision and what would benefit individuals, families and the community as a whole. Cresswell (1992) interestingly identified specific research problems such as gaining access to professionals and training issues for interviewers. Both impacted on the time to complete the project leading to an overall 12 weeks.

The New Economics Foundation (1997:65) identified a project in 1997 relating to participatory appraisal of needs and the development of action (PANDA). This was a community appraisal of drug issues in Withernsea, Hull. Interestingly the project revealed an established Appraisal Network, where project workers worked with young people, adults and community workers to identify gaps in knowledge about drugs and drugs related services. A diversity of routes were utilised to access local people including youth and leisure centres and places of work. Within this developed network the project focused on information giving relating to drugs and accessing services.

Barking and Havering Health Authority conducted two examples of rapid appraisal, the first focused on a review of mental health services steered by a multi-agency committee. There was no mention whether the committee included CHC, voluntary organisations or members of the public (Hamilton and Watts 1994). In contrast to work by Dale et al (1996) and Murray et al (1994) the health authority did not develop a multi-method approach within its appraisal. As with Cresswell (1992), the focus was interviews with 25 selected stakeholders including community leaders, professional and users/carers, however researchers did utilise an information pyramid (Murray

1999) as a structure for discussion (Hamilton and Watts 1994). The selection criteria for community leaders seemed narrow and focused on the police, voluntary organisations and minority group representatives. Furthermore, the ratio of professionals (community psychiatric nurses, GPs and social workers) to public was not identified. Interviewers were recruited from within the health authority (Hamilton and Watts 1994) although Cresswell (1992) and Murray (1999) advocated the use of community members to eliminate potential bias. Importantly, this method is linked to rapid identification of issues but the process still took five months to complete (Hamilton and Watts 1994).

The second example from Barking and Havering Health Authority utilised meetings and interviews within three separate localities for needs assessment for three care groups (children, women and the elderly). Meetings incorporated both professionals and members of the public in small group workshops, however the number participating in these groups was not identified and FSHA members facilitated the meetings (Haffenden 1992). Participants were identified as GPs, community staff, social workers, church leaders, representatives from voluntary organisations, consumer groups and CHC; there is no mention of minority ethnic groups (Haffenden 1992). Again the author did not identify how many informants were involved with interviews, although selection criteria as with Hamilton and Watts (1994), focused on members of the public who were best placed to have an overview of the community's needs. The exercise's validity was increased by the incorporation of a randomly selected group of interviewees, members of the FHSA also carried out the interviews - the use of in-house interviewers was linked to cost (Haffenden 1992).

As with citizens' juries, evidence from rapid appraisal identifies the capacity of informants to make realistic and practical recommendations, the strength of the method lies with its ability to identify a diversity of needs, rather than narrowly defined medical issues. Again the response to recommendations made by such public involvement was mixed, with health service initiatives less likely to show substantial outcomes.

Cresswell (1992) identified environment hazards, lack of local amenities, parental isolation and inadequate GP and health visiting services as some of the community's issues. Areas of development included professional relocation within the community; the introduction of a nursery and pre-school activities; facilities and resources for young people; improvement of park and play areas; development of a community newsletter and addressing environmental issues (Cresswell 1992). Although the report identified the setting up of a joint community and professional party to decide priorities, the literature was unable to identify specific actions as a result of the research.

As with Cresswell's research, Murray et al (1994) identified lack of amenities, environmental hazards and poverty as well as health problems. Service gaps included lack of chiropody and occupational therapy services, bathing facilities (also found in Haffenden (1992) report) as well as a lack of knowledge and uptake of some services. Murray (1999) assessed the outcomes of this work and found that all top priorities were achieved, which included a bus route through the estate; play areas; dog free zones; a new local supermarket; improved local general practices and care of people with mental illness (Murray 1999) as well as a drop-in club at the local community room (Murray 1999:441). This process also led to the creation of a local health forum of residents and various professionals, which aided the facilitation of change and was still running 4 years after the initial project.

Further research studies by Murray and Fraser (1997), focusing on the same estate, used rapid appraisal to examine local perceptions about mental health and illness. Outcomes included the development of a directory of local mental health services resources to all practices and GPs holding a series of meetings with local psychiatrists to voice community concerns. Murray's research highlights important lessons for public involvement, groups such as local forums and working parties do play a crucial role in ensuring recommendations become realities and that local ownership of the research process means that the actions are more likely to be implemented (Murray et al 1994).

Dale et al (1996) research on the 'out of hours' service also led to specific recommendations for service improvement, such as setting up a GP co-operative, improving existing services, establishing a central telephone answering advice service and improving multi-agency collaboration (Dale et al 1996:1209). The recommendations perhaps reflect the dominance of service providers within the appraisal, as they feel professionally orientated. Rapid appraisal by Barking and Havering Health Authority identified a diversity of social and health needs from care groups, such as lack of chiropody and bathing facilities, but also issues of substance abuse, environmental hazards, personal safety, suggesting the need for a multi-agency response to many of these issues. However, discussion on the impact of generated recommendations was vague, either they were part of a wider consultation programme (Hamilton and Watts 1994) or no impact was identified at all (see Haffenden 1992). As with citizens' juries, health authority commitment to identified recommendations appeared lacking.

Furthermore, the incorporation of diverse views, advocated in this approach (Murray 1999) was not always evident within the research reviewed. Again, Barking and Havering Health Authority appraisal of mental health users was characterised by limited public involvement and specific selection of informants, with the majority proxy users or individuals from professional groups (Hamilton and Watts 1994), similar conclusions can be made with Dale et al (1996) with a predominance of professional perspectives. Furthermore, although rapid, training was required both in relation to the technique itself and the methods incorporated (Cresswell 1992). Murray (1999) also asserted the importance of utilising rapid appraisal in deprived areas otherwise the technique could support unequal distribution of resources, but such criteria was not linked to the work of Hamilton and Watts (1994) or Haffenden (1992). Murray (1999) also made direct comment on the use of rapid appraisal by PCGs, suggesting that PCGs should by subdivided into groupings and neighbourhoods, where key informants were knowledgeable about local issues. Furthermore, priority should be given to the study and support of poorer communities within PCGs (Murray 1999).

3.7 Health Service Initiatives

3.7.1 Evidence from Local Voices

The document 'Local Voices' (NHS Executive 1992) can be seen as a catalyst for public involvement at the beginning of the 1990s with many initiatives developing following on from its publication. The document gave 19 examples of 'good practice' from health authorities and the FHSA in relation to public involvement, methods of involvement included forums; surveys; citizens' panels; focus groups; priority search; rapid appraisal; public meetings; newsletter and workshops (NHS Executive 1992: 18/22).

In reviewing this document, 16 out of 19 projects focused on information giving, gathering or exchange, supporting Coulter (1999a) assertion that the projects failed to facilitate citizen empowerment. Indeed, five examples had no direct involvement at all focusing on complaints review, newsletter, reports, job creation and strategic development (NHS Executive 1992:18/22). Only 5 out of 19 examples included members of the public, defined as residents, community groups and by passers. Overall, the examples reflected a narrowly defined 'public' focusing on patients, Community Health Councils, voluntary organisations and different professional personnel including teachers, police and social workers. Furthermore, the examples reflected an over-reliance on the voluntary sector, particularly the CHC, with many of the projects focused on specific issues that had been identified by health professionals or management, a view supported by Jordan et al (1998). Only one project, a consumer involvement programme, provided evidence of an attempt at on-going consultation.

Weaknesses within 'Local Voices' were also highlighted in the literature, criticism focused not only on the projects failure to empower citizens (Coulter 1999a, Barnes 1999), but highlighted an unchanged health authority power base, with the authority making the decisions on whether or not to take recommendations into account (Coulter 1999a).

Analysis of the document identified only one example showing how involvement had made actual changes. Jordan et al (1998) stated that although the health authorities had increased local consultation, quality was dubious with a strong emphasis on one-off consultation exercises, analysis showed at least 11 out of 19 relate to such one-off initiatives.

3.7.2 Commissions & Consumer Involvement

Taylor (1995) presented an executive summary of consumer initiatives in the 1990s, which were implemented by six Commissions in the former Wessex Health Region. The report incorporated interviews with senior managers and specialist workers responsible for consumer involvement in each commission and documentary analysis of initiatives (Taylor 1995). However, it did not state whether the views of the consumers involved in such initiatives were incorporated within the summary. Taylor (1995) provided evidence of an organisational approach to involvement, identifying more comprehensive actions than 'Local Voices' (NHS Executive 1992) with the incorporation of a number of methods of involvement facilitating different levels of participation.

The Commissions addressed specific areas such as needs assessment, purchasing and commissioning as well as broader issues such as public accountability (Taylor 1995). However, like 'Local Voices' (NHS Executive 1992), evidence within the report reflected a predominance of information exchange rather than active consumer involvement and a lack of consistency in approach to such initiatives. Although incorporating a number of methods of involvement, the organisations fell short of a strategic approach.

The executive summary revealed a wide-ranging research study, with information gathered on seventy-four projects (Taylor 1995: Section 8.3) and consumer involvement initiatives were divided into five information categories: -

BOX 15

Types of Consumer Involvement Initiatives

- Service reviews and service feedback
- Information and public relations
- Alliance building
- Locality/patch projects
- Internal support/coordination for consumer involvement (Taylor 1995:54)

Information giving was the aim for over half of the projects and a main function of 20 initiatives: again doing little to facilitate citizen empowerment (Coulter 1999b). The study identified major variations in the production of accessible consumer information. Three commissions had developed consumer help lines, which were viewed as demonstrating openness and credibility (Taylor 1995). A number of difficulties were identified in regards to public meetings such as the ratio of organisational effort in relation to low turnout as well as concerns with the potential for confrontation (Taylor 1995). Some of the reasons for lack of public attendance are identified by Broadbent (1998) who investigated trust board meetings, with variability in the accessibility of information regarding meetings, specifically date, time and venue. Alternative strategies to public meetings focused on developing informal contacts with existing community groups prior to, or instead of, holding public meetings (Taylor 1995).

There was no evidence that Commissions followed any specific criteria in the choice of involvement methods, implementation was linked to existing expertise or the method favoured by the Commission (Taylor 1995). Again, the report reflected the predominance of 'one-off' initiatives with little mention to on-going consultation. Voluntary groups were identified as providing a straightforward and fast route to consumer involvement, however the representativeness of such groups is questioned

(Chambers 2000). This was echoed by some respondents' concerns about the risk of over-reliance on voluntary organisations or on a single user group (Taylor 1995).

Developing alliances and joint working was identified as one of the main aims of just under half of all projects and a main function for 47 of them. Joint working included social services departments, local authorities, CHCs and the voluntary sector. Taylor (1995) identified a mixed reaction to working relationships with user groups and voluntary organisations. The latter being seen as important, particularly regarding recommendations on consultation methods. However, as with views of CHCs, there were some concerns in relation to vested interests linked to such organisations (Taylor 1995).

Locality frameworks/patch approaches were utilised by some of the Commissions in supporting primary care purchasing, a further example of patch areas was seen within 'Local Voices' (NHS Executive 1992:22). Two Commissions had used a patch approach in relation to needs assessment and patch workers had been utilised by one of the Commissions to liaise with users in service reviews. There was also use of the GP as a consumer proxy in relation to locally sensitive purchasing and the GPs own activities in relation to consumer involvement (Taylor 1995). However, the focus on the voluntary sector and professionals in defining needs reflected an inability or reluctance to consult more widely.

Internal mechanisms within the organisations again reflected some diversity. A number of Commissions had subgroups related to consumer involvement such as multi-agency steering groups, non-executive groups and consumer involvement task forces (Taylor 1995). However, there was no mention of any attempts in the report of co-opting members of the public on to such internal groups and although it suggested that non-executive members played a significant role in consumer involvement activities, their own representativeness has been questioned (Hogg 1999).

Throughout the report no evidence is provided as to the effects of the consumer involvement within the six Commissions. However, the executive summary made a number of recommendations for further consumer involvement initiatives: -

BOX 16

Report Recommendations

- Senior management responsibility for consumer involvement at both a strategic and operational level
- Acceptance that community involvement requires skill, confidence, resourcing and training
- Mechanisms for co-ordinating consumer involvement activities are essential to maximise the benefits and make the best use of resources
- Consumer involvement requires systematic and regular monitoring, which would also create useful organisational learning
- More attention could be given to the role of different kinds of consumer representatives
- The role of providers in developing consumer involvement needs to be better understood to avoid duplication, confusion and user consultation fatigue (Taylor 1995:72/73)

Further emphasis is placed on the need to develop effective networks across Commissions to share experience in relation to consumer involvement as well as the development of expertise such as non-executive members and workers within the voluntary and statutory sector (Taylor 1995). More attention had to be given to the way the results of consumer involvement initiatives were fed back to the participants and how they were used in the commissioning process (Taylor 1995). The recommendations were disappointingly repetitive suggesting a lack of learning from available research and literature. Taylor (1995) perhaps answers this observation by suggesting pressure from central government to demonstrate results may have prejudiced and slanted consumer involvement towards short-term and superficial achievements and advocated long-term goals with a focus on quality rather than quantity. The reports recommendations potentially provided a useful guide to PCGs in relation to initiating effective involvement.

3.7.3 Consumers in Research

'Involvement works' a report on the Standing Group on Consumers in NHS Research was published in 1999 (NHS Executive 1999), the initiative emerged from the Patient Partnership Strategy in 1996 (see Section 1.19). This report reflected consumer involvement in a number of projects - research and development priorities, health technology assessment, breast cancer trials, Cochrane Collaboration, FOLK.US, DISCERN, infantile arthritis (NHE Executive 1999:5/18). As with many top-down initiatives there was, again, a strong emphasis on information-exchange. Furthermore, disappointingly research was narrowly defined focusing almost exclusively on disease and treatment.

The Directorate at Northern and Yorkshire Region (NHS Executive 1999:5) utilised a mixed methodology to identify a consumer perspective regarding research priorities. This included a questionnaire to consumer organisations, consultation via local meetings and focus groups (organised by CHC). The priorities were identified as: -

BOX 17
Research Priorities

- Service delivery in general practice and community services, and the provision of patient information
- The health needs of older people, people with chronic disease and people with mental health problems
- Medical conditions – cancer, mental health and heart disease (NHS Executive 1999:5)

The report again revealed that informants were able to make realistic prioritisations. However, as with Taylor (1995) concerns focus on an over-reliance on voluntary organisations; patient information and an emphasis on disease and care are indicative of such organisations (Lupton et al 1998), leading to concerns relating to the neglect of vulnerable groups and minority ethnic communities. However, the region now required that all applications for funding of research projects must include a statement of how consumers will be involved (NHS Executive 1999:5).

Similarly, the Health Technology Assessment (HTA) Programme had involved consumers in the identification of research questions (NHS Executive 1999:7). The project reflected organisational learning with findings suggesting the most effective

way of identifying research questions was face-to-face discussion with consumers. Researchers identified language barriers and consumer needs, which included adequate training and time, better briefing and on going support (NHS Executive 1999:7). However, none of these observations are new or unique, perhaps, suggesting the need to move on from learning what has already been learnt.

The consumers' ability to offer a different perspective was clearly highlighted within the HTA programme and the Cochrane Collaboration. The HTA programme also included consumers in research proposal review, finding that review forms were inappropriate for consumer contributions. Furthermore, consumers were able to identify issues regarding patient perspective; social contexts; information and support needs; long term outcomes and dissemination of research findings, such issues were not always addressed by professional referees (NHS Executive 1999:7/8).

Similar findings were found by the Cochrane Collaboration, an organisation assisting effective public decision-making through the production of systematic reviews relating to healthcare interventions (NHS Executive 1999:13). The benefits of involvement again were seen as a different perspective, with consumers presenting a reality check; challenging jargon; pretentiousness; increasing relevance and accessibility of reviews and assisting in the dissemination of results to the public. Consumer activity included topic identification for reviews, protocol development as well as preparation and maintenance of the reviews. Such activities, however suggested a level of expertise and knowledge relating to research - the profile of informants was not given in the report.

In reviewing the level of involvement of the projects discussed by the report, the strongest emphasis is on information giving. Examples such as the design of breast cancer trials focus on the importance of adequate information for patients, with a booklet being produced (NHS Executive 1999:10). Again, with the Cochrane Collaboration, the main emphasis was the improvement of communication and information between consumers and health professionals. Other projects also focused on information giving, such as the development and analyse of disease education programmes for children with chronic arthritis (NHS Executive 1999:14). FOLK.US was a collaborative project, which included consumers, researchers, NHS personnel

and social services representatives. Its aim were to increase awareness in the research community about consumers' views, values and knowledge as well as networking good practice in relation to partnership between consumers and researchers (NHS Executive 1999:14). The DISCERN project (NHS Executive 1999:18) focused on questionnaire development enabling patients and information providers to assess quality written information regarding treatment choices and a range of experts and patients developed and tested DISCERN (Gann 1998).

3.8 Associated Literature Reviews

Jones et al (1987) posed the question, does public participation actually improve services and consumer satisfaction. At the time of their literature review in the 1980s there were limited research findings to support this assumption. Johnson (1997) gave a literature review of local involvement in health care settings reviewing 116 reports and articles and summarised that a cultural shift had been identified, however some barriers to successful local consultation were highlighted (Johnson 1997). Many senior managers claimed to be highly committed to local consultation but this was not always manifested in their strategies. Furthermore, some front-line staff appreciated being given insight into user's perspectives while others found it difficult to accept criticisms of their professional behaviour (Johnson 1997). Most users appreciated the opportunity to have their voices heard, however some were suspicious about health authority's motives in relation to their involvement (Johnson 1997).

Summary

The review of research concerning public involvement reflects a diversity of approaches. Evidence provided tends to directly challenge paternalistic assertions that members of the public are unable to understand complex health issues, particularly, if deliberative, informed approaches are utilised and participants are adequately supported and briefed. Indeed, informants go beyond understanding and show both an ability to offer a new and different perspective as well as make realistic and practical recommendations for action. However, issues of representativeness remain in some projects, reflecting a narrow cross section of the population and low public awareness. Those who do participate find involvement rewarding on a number of levels.

Examples such as the Peckham Pioneer Health Centre and some rapid appraisal initiatives were able to identify actual change in specific communities in relation to service development, community services and health. However, research in this area also highlights continuing difficulties, particularly with funding. By comparison, research evidence, articles and reports of top-down initiatives suggest a focus mainly on consultation and information giving rather than direct participation. Furthermore, reviewed reports on citizens' jury pilots and rapid appraisal initiatives instigated by health authorities were unable to identify specific changes. Indeed, there was little evidence available within the review to suggest how such initiatives had directly influenced decision-making by health organisations. The lack of influence was not lost on informants; research identified a palpable scepticism regarding the impact of involvement, perhaps, highlighting that local ownership is needed to effect change (Murray 1999).

Methodological difficulties were also evident within some of the research reviewed. Specifically, it was clear that some of the methods used within public involvement initiatives had been inappropriate. However, issues linked to the calibre of the research and approaches utilised are not insurmountable. Also little of the research evidence reviewed reflected a continuous and strategic approach in relation to public involvement. There were research projects, which highlighted the use of a mixed methodology, but they focused on single issues such as needs assessment, purchasing and commissioning although generating multiple solutions. Many of the examples given were ad hoc or one-off exercises, some were long standing but focused again on one specific group or community. Those looking for guidance of a strategic approach, incorporating multiple methods featuring a diverse public, would be hard pressed to find it.

CHAPTER FOUR

The new NHS & Public Involvement

Introduction

The complexity of public involvement both conceptually and practically, did not affect its sustained position within government health policy. Following Labour's victory in the May 1997 general election, public involvement was portrayed as a key component (Gann 1998) that would enable a democratisation of the health service and assist with achieving health targets (Brooks 2001). Decisions made within health policy again had to be placed within the socio-economic and political context of the time. Third Way politics, globalisation and public scandals were influential factors as all were to play a role in shaping the development and implementation of public involvement in the health service in the late 20th and early 21st century.

During this time the focus and thrust of health policy was primary care (Brown 1999, Calnan and Gabe 2001) and the emerging changes would mean major restructuring of its organisational framework (Meads 1999, Willis 1998), with over four hundred primary care groups to be established across England by April 1999 and the first Primary Care Trusts emerging in April 2001. Lay membership was visible at board level and the new primary care organisations were charged with the development of a public involvement strategy. However, government guidance was to prove vague, with few concrete facts available regarding the development or extent of public involvement (Fawcett and South 2005). Furthermore, although government policy advocated decentralisation and devolution, centralised control continued to dominate primary care (see DoH 1997, DoH 1998a, Doh 1998b). Finally, health service scandals, associated reports and reactive policymaking were to force the issue of public involvement, with a re-defined concept impacting on the new primary care organisations (Milewa 2004, Baggott 2005).

4.1 Globalisation, Third Way Politics & Health Policy

Public involvement was integral to 'Third Way' politics; such political assumptions were linked to 'neo-liberal modes of government' (Stenson and Watt 1999:19) and were evident within New Labour health policy. Two influential concepts were linked to such politics: globalisation and individualisation (Giddens 1998) which both, in turn, spawned key interrelated concepts such as citizenship, devolution, deregulation,

community, democracy and risk with public involvement pervading all areas. These themes were particularly apparent in the analysis of health policy in the late 1990s.

Social theorists have documented a rapid social change over the last two decades (Fagan and Lee 1997, Lewis 2000), with the work of Giddens being particularly influential (Peterson 1997) on New Labour policy. Fagan and Lee (1997:145) suggested that the concepts of globalisation, individualism and diversity had replaced those of nation, the family, capital and class. The emergence of individualism was linked to the breakdown of collective identities through contact with new cultural forms (Fagan and Lee 1997:145) as well as the view that the world was becoming more uncertain, flexible and risky (Turner 1992). Such changes also had implications for public involvement, which was seen as a duty for individual responsible citizens (Brooks 2001).

4.1.1 The Influence of the Concept of Risk on Public Involvement & Policy

The emergence of risk as a basis for personal decision-making was also highly influential in constructing the public involvement agenda. The notion of risk incorporated a need to make some sense of the global context of the time and within health promotion and community development there was a strong focus on 'at risk' populations and 'risky' situations (Peterson 1997). However, Turner (1992) identified a profound tension between governmentality and a risk society. A risk society based on deregulation and devolution, reflected in recent health policy (see DoH 1997), often required more subtle and systematic forms of control e.g., regulatory systems of quality (Turner 1992). On the one hand, Primary Care Groups would have devolved powers to improve health and develop and commission services, but these new smaller bodies would come under greater centralised control. With national targets for health improvement identified within 'Our Healthier Nation' (DoH 1998a) as well as national service and performance frameworks identified with 'A First Class Service' (DoH 1998b).

However, such societal changes were not without difficulties. New market opportunities and deregulation had meant that some of the most vulnerable people in

society were being expected to sort out crucial arrangements at their own risk and without professional intervention (Jones Finer 1997). Jones Finer (1997) posed the question of who was being empowered and at whose expense. Without adequate resources and regulation or coherent philosophy, freedom and flexibility could look like abandonment for some groups, those most dependant on the welfare state. Public involvement within this definition becomes highly individualised and potentially ignores those experiencing social exclusion.

4.1.2 Redefining Citizenship

Globalisation led to a redefining of citizenship focused on rights and obligations, within Third Way politics (Giddens 1998). Again, this was reflected within health policy. The Green Paper 'Our Healthier Nation' (DoH 1998a) identified the 'Third Way' and emphasised partnership and roles between government, local communities and the individual for improving health, indeed, a three way contract was propositioned (Gabbay 1998, Coote 2000b). The ideals of rights and obligations were also embedded in the terminology of the 'stakeholder', which also pervaded health policy, although previously established in previous Conservative policy rhetoric (see Section 1.18). The notion of stakeholding emphasised the legitimate interests of citizens in issues surrounding the development and delivery of services (Sanderson 1999). Importantly, stakeholders needed to be able to participate fully, with judgements reached through a process of negotiation (Sanderson 1999). This was seen as a 'new' consensual approach to social policy: everyone deserved a fair chance. However, rules were important and communities and individuals had to plan to be self-supporting (Jones Finer 1997). Public involvement viewed from this perspective suggests that participation is conditional with individuals and communities obligated towards self-care.

4.1.3 Devolution, Decentralisation & Community

Globalisation was seen by some as a potential catalyst for a downward devolution of power, with such power moving to local communities (Giddens 1998). With the idea that self-government could allow communities to regenerate local areas and neighbourhoods both socially and materially (Giddens 1998). There was also an international context to such regionalisation, with authors such as Smith (1999b)

maintaining that global implementation of Agenda 21, in relation to environmental and health issues required local commitment. Growing distrust towards public institutions at national and local government levels further explains the enthusiasm for local agency input (Smith 1999b). In terms of public involvement devolution had the potential to increase public accountability within NHS organisations. The NHS Executive/IHSM and NHS Confederation report 'In the Public Interest' (1998) identified that effective scrutiny and organisational accountability needed to acknowledge local circumstances and include local people.

The influence of devolution and community could be seen with the introduction of the concept of Primary Care Groups. The new organisations were to be formed around natural geographical communities (HSC/065 1998), with local health professionals having devolved powers for commissioning and developing services for the local community (DoH 1997). Working in partnership was seen as an essential component, not only between health and social services but also between health workers and the public. Such mixtures of community development and local decision-making had the potential to address inequalities (see 'Our healthier Nation' DoH (1998a)). However, a potential by-product of devolution came in the form of fragmentation, increased local bureaucracy or uneven community development (Giddens 1998). Giddens (1998) acknowledged civic involvement tended to be less in marginalised communities. In advocating Third Way politics, he identified that government needed to support and encourage initiatives within these marginalised areas, and perhaps can be tentatively linked to the development of Health Action Zones in 1998.

Community is, again, a highly contestable concept having multiple definitions. Authors such as Fox and Miller (1995) emphasised the theoretical nature of community - a way for cultural development, participation and interaction. Communitarians want all citizens to be involved and believe that involvement is essential to fulfil the developmental potential of human beings and assumed universality. However, the growth of poverty and unemployment, combined with 'race' and gender exclusion were to undermine the basis for shared citizenship, epitomised within the concept of community (Wilson 1997:183). Fox and Miller (1995) advocated that the idealism of communitarians seems misplaced; noting citizen indifference, the state of community was questionable, '... essentially an idealistic

stained-glass window nostalgia' (Fox and Miller, 1995:36). Such debates suggest that mobilising a public involvement strategy within local communities could prove contentious for the new primary care organisations.

4.1.4 Democratising Democracy

The phrase 'democratising of democracy' (Giddens, 1998: 72) was utilised in advocating the expansion of public involvement and a move to greater transparency and openness in relation to decision-making. Indeed, Giddens (1998:75) emphasised a need to re-establish more direct contact with the public, which could be facilitated through 'experiments with democracy'. The NHS Executive/IHSM and NHS Confederation (1998) in its review of public involvement also advocated the opening up of decision-making; this included finding new ways to include citizens in the planning and provision of services. PCG/Ts were well placed to initiate or become involved with such experiments in public involvement.

4.2 The new NHS & Primary Care Groups

The concept of primary care groups (PCGs) was introduced in the Governments White Paper 'The new NHS: Modern and Dependable' (DoH 1997) as part of the NHS reforms. The paper revealed several important themes such as partnership, local responsibility, quality and efficiency. Although it heralded the demise of the internal market (Dixon and Mays 1997) and competition between providers, the enterprise society (Jones 2000:11) continued to influence policy. The White Paper advocated co-operation and partnership in relation to care provision, however it would take place within a mixed economy with a continued purchase/provider split (Dixon and Mays 1997, Bevan 1998, Roland 1999). Six main principles guided the change: -

BOX 18
Guiding Principles for Change

- To renew the NHS as a genuinely national service
- To make delivery of health care against national standards a matter of local responsibility
- To get the NHS to work in partnership
- To improve efficiency, every pound is spent to maximize the care of patients
- To shift the focus on to quality of care, excellence is guaranteed to all patients
- To rebuild public confidence (DoH 1997:11)

Although rebuilding public confidence was one of the guiding principles of the document and a strong emphasis is placed on organisational openness and transparency (New 1999), there was little discussion on how public involvement fitted in with this new vision. Public meetings were the only mechanisms for consultation mentioned in the White Paper, 'an inadequate means of genuinely engaging communities in the health issues that matter to them' (Fisher et al 1999:749).

The document also mirrored Conservative health policy focusing strongly on the improvement in quality of services (Jones 2000) and identified three action areas: -

BOX 19
Action Areas

- National Standards & Guidelines – the development of National Service Frameworks to address issues of access and quality of care nationally
- A local drive for quality – GPs and community nurses would collaborate and shape local services within new organisations – Primary Care Groups. There would also be explicit quality standards in service agreements between PCGs, health authorities and NHS Trusts. A new system of clinical governance would be introduced to ensure clinical standards would be met
- New organisations – in the form of the CHI, which would oversee and support the quality of clinical services, with powers to intervene (DoH 1997:17 - 23)

Although, health policy in the late 1990s heralded the re-emergence of local responsibility and decision-making, the action areas identify a strong emphasis on central control. The paper revealed a number of organisational changes, which included the introduction of two new organisations. A new National Institute for Clinical Excellence (NICE) would lead on clinical and cost effectiveness. The Commission for Health Improvement (CHI) focused on the support and overseeing of the quality of local clinical services, with the ability to intervene where problems remained unresolved. Other centrally controlled initiatives focused on the introduction of an annual national survey and new NHS Charter (DoH 1997).

A number of other strategies were also introduced for maintaining and improving quality such as national standards and guidelines (DoH 1997). Treatment would now be evidence-based and linked to National Service Frameworks (NSFs) with standards to measure success labelled National Performance Frameworks (NPFs). Indeed, the term performance appeared 88 times in the document (McColl et al 1998).

Measurement using these national frameworks would include a mixture of centrally defined sanctions and incentives. Such NPFs would also include aspects of public consultation such as patient experience (DoH 1997). Although government rhetoric highlighted citizenship such policy review identifies public involvement continuing to be defined within a consumerist perspective, with emphasis on quality and service responsiveness (Milewa 2002b).

Primary care groups were to develop across England; comprising all GPs, they would hold a single unified budget and organisation functions were identified as: -

BOX 20
PCG Functions

1. To improve the health of their community
2. To develop primary and community health services
3. Commissioning of secondary care services (HSC 1998/222:3)

Analysis of government documentation suggested the origins of the PCGs were not clear. However, their development was seen by many as a natural progression from a variety of previous primary care initiatives (see Section 4.3) as well as an acceptable replacement to GP fundholding and the inequalities inherent in that system (Leese et al 1999, Roland 1999).

Again, involving all GPs in commissioning/purchasing through non-voluntary participation in PCGs strengthened central control over quality and access to clinical care (Dixon and Mays 1997). There was evidence of devolved responsibility to local levels but PCGs would have to operate within a strong governmental framework. This had the potential to threaten the autonomy of local initiatives and public involvement. Such observations were supported by Lenaghan (1999:11), suggesting that although the government was encouraging local, participative democracy these developments had been accompanied by the centralisation of some policy making processes, with a potential clash between local and national priorities.

Furthermore, Rhodes and Nocon (1998) asserted that the new NHS failed to give users a stronger public voice to the design of health services strategies with emphasis placed on accountability rather than user contribution. The assertion that local doctors and nurses were best placed to assess health needs was also strongly criticised.

Indeed, the competence of experts in health needs assessment had often been challenged (Percy-Smith and Sanderson 1992). Evidence from GP fundholding suggested professional indifference to needs assessment, with priorities being predominantly medical (Fisher and Gillam 1999, Behan and Loft 1999). Such assessment often did not entail going anywhere near the local population (Jordan et al 1998). There were also concerns over a potential return to paternalistic attitudes with the document strengthening the role of health professionals by giving them the authority to speak on behalf of patients (Rhodes and Nocon 1998).

4.3 Professional Perspectives

A major professional criticism of government directives was their vagueness and lack of clarity in relation to aspects of PCG operationalisation (Chisholm 1998). It is, perhaps, for this reason that much professional discussion linked to previous pilots in primary care. Fundholding, locality commissioning, total purchasing and multifunds had all emerged as alternative primary care models (Roland 1999, Smith 2000), although, such models provided extremely limited examples of public involvement (see Section 4.4.1). Both Light (1999) and Warden (1999) highlighted concerns regarding the pace of organisational change and tight timetabling. However, ready or not, Meads (1999) concluded PCGs would be instrumental in delivering a new mixed economy of frontline care. Brown (1999:169) supported this view suggesting that 'efforts to involve the public in primary care must relate to general practice as the organisational hub of first level health services in the UK'. However, he voiced concern over the lack of clarity of how initiatives at the practice level should relate to the PCGs.

Little discussion in the review of professional literature focused on the benefits of the new structure to patients or the public. However, a number of comments highlighted the marginal nature of public involvement in primary care and the challenging nature of working with different community interests (Fisher and Gillam 1999). Fisher et al (1999) observed that few GP fundholders involved patients in purchasing. Smith (1999) suggested the challenge for the PCG was true representation; special interest should not be at the expense of the whole population. Whilst welcoming the initiatives of the lay member and open board meetings, in time more sophisticated methods of consultation were needed (Smith 1999a). Some concerns focused on the potential

isolation of the lay board member (Fisher et al 1999, Persaud 1999) and the need for such individuals to be adequately supported. Persaud (1999) also identified the implausibility of one lay member reaching minority groups. This suggested a number of implications for public involvement. PCGs would have to encourage greater professional contact with the public, hopefully through initiating imaginative and effective methods of involvement. Lay members needed to be accepted and integrated within the new board structure, however over reliance on such individuals and specific groups would perpetuate problems with representation.

4.4 A Trilogy of Guidance

The first details of PCGs' function and potential development came in three health service circulars (HSC) throughout 1998, published by the NHS Executive.

The initial guidance highlighted and reiterated the options/levels for the formation of PCGs: -

BOX 21
PCG Operating Levels

1. At minimum, support the Health Authority in commissioning care for its population, acting in an advisory capacity
2. Take devolved responsibility for managing the budget for health care in their area, formally as part of the Health Authority
3. Become established as freestanding bodies accountable to the Health Authority for commissioning care.
4. Become established as freestanding bodies accountable to the Health Authority for commissioning care and with added responsibility for the provision of community health services for their population (HSC 065 1998: 22)

4.4.1 Previous Primary Care Initiatives

Within HSC065/1998 guidance there was the suggestion that assessment and evaluation of commissioning pilots and Personal Medical Services (PMS) pilots would assist PCGs with their development and operation. Such pilots could provide examples of new approaches and practice opportunities. However, a review of assessments of such pilot schemes found little evidence of previous public involvement (see Section 3.4).

4.4.2 Board Membership & Lay Involvement

PCGs were charged with increasing public consultation in relation to local services (HSC 065 1998). More specific public involvement was reflected at board level, with each governing board comprising of one lay representative (HSC 139 1998) and each PCG requiring to develop and implement a public involvement strategy. Direction on governing board membership was delivered in HSC/139 1998 published in August: -

BOX 22
PCG Board Structure

- 4 to 7 GPs
- 1 to 2 community nurses
- 1 social service officer nominee
- 1 lay member
- 1 Health Authority non-executive
- 1 PCG chief officer (HSC/139 1998:9)

The uneven power relationship between professionals and non-professionals within the board structure was evident, reflecting the dominance of GPs and health professionals in general. Medical dominance was further cemented by Alan Milburn's agreement in June 1998, identifying that GPs should have the right to decide whether they would be in the majority on PCGs boards and whether they wished to hold the chair (Beecham 1998a).

The lay member was seen as addressing public accountability and confidence in governing arrangements. Guidelines regarding the appointment were limited; the position was open to any member of the public except GPs, nurses, and NHS Staff (HSC 139 1998:11). Potential candidates needed to live in the geographical area of the PCG, although holding another community or local representative position e.g., district councillor or CHC member would not disqualify individuals from applying. Guidance slightly elaborated on the role of the lay member, suggesting such individuals should represent the local community, users and carers. Further elaboration appeared in 'Patient and public involvement in the new NHS' (DoH 1999a) suggesting that although patient and public involvement was the responsibility of the whole PCG (DoH 1999a:11), the lay member could take a lead role in engaging with patients and local communities. The focus on the lay member to lead on public involvement seems unsupported by any evidence to their suitability for this position.

Furthermore none of the guidance identified a job description, specific skills or expertise.

4.4.3 Public Involvement Strategy

There was also greater clarity in relation to public involvement strategy within the supporting guidance of HSC139/1998, suggesting that PCGs could play a key role in communicating with local people and ensuring public involvement in local decision-making. Importantly, the guidance demonstrated the relinquishing of such responsibility to each PCG, who would determine locally how best to achieve involvement of users and public, which left the potential for a wide variation in approach. The guidance also established that involvement should be regarded as an integral part of PCGs activities, the aim being to develop a continuous dialogue with local communities rather than fulfilling one off activities (HSC139/1998:25). PCGs were: -

BOX 23
PCG Public Involvement Strategy

- To put in place plans for the early, systematic and continuous involvement of users and the public
- To be able to demonstrate how carrying out their role they have involved users and the public
- To provide feedback to users and the public on the outcome of their involvement (HSC 139/1998:25)

Other government guidance elaborated on a communication strategy: -

BOX 24
PCG Communication Strategy

- Have strategic plans for involving and communicating with patients and the public
- Be able to demonstrate how they have done this and provide feedback on the outcome of involvement
- Seek to develop good working relationship with their local CHCs
- Provide sufficient resources and support to lay member who lead on patient and public involvement (DoH 1999a:11/12)

In analysing the above general statements the strategy not only has to reflect efforts of involvement, but evidence of effective communication with a number of stakeholders such as patients, the public and CHC, with adequate support and the provision of

resources. This suggested that PCGs would have to develop not only a public involvement strategy but combine this with a communication plan. Information sharing and transparency were strong themes in relation public involvement and organisational commitment (Chambers 2000).

4.5 PCG Configuration

On April 1 1999, 481 PCGs became operational in England (Audit Commission 2000) and a number of research reports provided early analysis of the configuration of PCGs. A report by Arora and Gillam (1999) focused on the establishment of the 66 PCGs within the London area, health authority managers, via questionnaire, were asked to identify which configuration criteria, identified in HSC065/1998, they found difficult to meet. These were: - size, natural communities, public involvement/democracy and agreement of all stakeholders (Arora & Gillam, 1999:20).

The report identified a minimum level of public consultation regarding configuration of PCGs, usually involving CHCs. Other attempts at engaging the public identified were: - distribution of the consultation document, open meetings/attendance at public meetings, advertisements in the local press and exhibitions at the health authority and local library (Arora & Gillam, 1999:21). Some health authorities were concerned with a lack of representation from minority ethnic groups and gaining the views of the voluntary sector. A recurring theme within the study was the diverse range of natural communities and the importance of developing techniques for sensitive local needs assessment (Arora and Gillam 1999).

Campbell and Proctor's (1999) research into the development of four PCGs within Bradford, found public consultation for configuration more encouraging, including more than fifty organisations. Public opinion was gained from a wide range of representatives of the local population – although none are identified specifically (Campbell and Proctor 1999). The researchers reported a considerable interest in the development of PCGs, by the level of attendance at over 100 public and professional meetings – a direct contrast to Arora and Gillam findings. Consultation with lay people happened relatively late in the consultation exercise with time and workload identified as the main difficulties (Campbell and Proctor 1999).

4.6 The Rapid Pace of Evolution

It became clear within this research project and literature review that the transition of PCGs to trust status would occur at a rapid pace and after a three-month preparatory period, the first PCTs became operational on 1 April 2000. They were freestanding, legal, statutory, bodies accountable to respective health authorities, with a second wave operational in October 2000. Their functions remained the same overall to that of PCGs to allow continuity of developed strategic plans, however, at Level 4 PCTs would be able to provide services, run hospital/community services and employ staff.

4.6.1 PCT Governance

Government documentation identified clear differences between PCGs and PCTs in relation to governance arrangements with each PCT having a governing Board and an Executive Committee. The lay experience would significantly change, unlike PCGs, PCT boards would have a lay majority: -

BOX 25
PCT Board Structure

- Lay Chair
- A majority of non-executives
- Chief Executive
- Director of Finance
- 3 professional Executive Committee members (DoH 1999b:18)

However, there would be no lay representation on the professionally dominated Executive Committee. Moreover, local accountability appeared to be sacrificed once again in favour of centralised control as the Lay Chair and non-executives were again to be appointed by the Secretary of State, with the related lack of democratic credentials (Starey and Marchment 1999). In analysing the job description of the non-executive member and Chairs, lay members needed to be highly skilled and with expertise in a diversity of areas, therefore, exclusive in nature. No specific training needs were identified for either role or that such training should be ongoing.

The role of the board was described as supervisory, to provide strategic oversight and verification to the work of the Executive Committee (DoH 1999b). Its responsibility was to ensure the key requirements of public accountability; public involvement and probity were fully met through a publicly transparent system as well as through

external relationships with other stakeholders (DoH 1999). The membership of the Executive Committee differed depending on whether the PCT was operating at Level 3 or 4: -

BOX 26
Executive Committee (Level 3)

- Chair
- Chief Executive
- 10 professionals – up to 7 GPs and at least 2 nurses
- Director of Finance
- Social Services Representatives (DoH 1999b:18)

At level 3 the Executive Committee again remained dominated by GPs with professional allied to medicine not specifically identified (Willis 1999). Also the absence of a lay representative was noteworthy, although the co-opting of members still remained an option.

BOX 27
Executive Committee (Level 4)

- Chief Executive
- Director of Finance
- Chair
- 10 professionals – up to 5 GPs, 5 other clinicians, with at least 2 nurses (DoH 1999b:18)

This perhaps reflected a more equal power distribution between health professionals (see Box 27). However, the governance arrangements reflected the division and segregation of lay and professional representation, with a potential for this to impact on the development of an integrated strategy on public involvement both positively and negatively. In analysing the competencies for professionals, the need for knowledge of public involvement or associated methodologies was not explicitly stated. There were some limited extensions to the powers of the CHC, however, again government documentation failed to give access as of right to the CHCs in this new organisational development (Commission for Representing the Public Interest in the Health Service, 1999).

The consultation period was established as 2 to 3 months and the form of the consultation document was for local determination. The aim of the consultation was to provide a transparent and open process, which captured the views of all stakeholders (HSC 1999/207:3). Health authorities had to collate the consultation responses and make a report to the Regional Office within two weeks, an extremely tight timescale and the report also had to be available to the public.

4.7 Reactions to Trust Status

The response to trust status formed a continuum from feeling pressurised and railroaded (Davies 1999, Starey and Marchment 1999, Yamey 1999) to ready acceptance (Meads 1998). Proctor and Campbell (1999) in their research, identified that of Bradford's PCGs 3 out 4 were giving serious consideration to preparing for PCT as soon as possible and they were positive about the potential outcomes. Meads (1999) confirmed such findings, highlighting that the predominant aspiration in his research project was to become a PCT in a short time with 2001 being the most frequently cited target date. Many advocates of trust status picked up on the government rhetoric 'new opportunities and greater flexibilities to shape services' (HSC 1999/246:4) as arguments to move forward. One of the biggest incentives was seen as service development such as integrated service delivery (Kendrick and Hilton 1997, Audit Commission 2000), direct investment in IT systems, premises and employment of staff (Wall 1999) as well as increasing GP commitment (Audit Commission 2000).

The literature review again revealed little discussion focused on the impact of trust status on public involvement. There was some emphasis on public accountability (Wall 1999). Building public confidence was seen as essential as PCTs would be seen by communities as the local expression of the NHS and would have a duty to communicate accordingly and ensure local decision-making where possible (Wall 1999). It was clear that primary care organisations were looking forward to the greater level of independence inherent in trust status. However, this organisational transition would be played out in an environment of increasing central regulation and the next sections identify a number of influential issues that were to effect public involvement.

4.8 Continuing Central Control – Information Issues

Information giving was a recurring theme within health policy (Gann 1998) and developing and consolidating alongside PCG/Ts were a multitude of government initiatives, organisations, charters, surveys and legislation relating directly to information. However many of the government information initiatives within the 1990s, were specifically aimed at professionals and/or patients rather than the public. These included the Cochrane library, NHS Centre for Research and Dissemination (presenting reviews and publishing the Effective Care Bulletins and Effectiveness Matters), CHIQ, the National Research Register, National Electronic Library for Health and the NHS Website. Such initiatives could be seen as government and professional attempts to address the media explosion and particularly the effects of increasing public access to different multimedia forms such as television, E-mail and the Internet (Coulter 2000). Dyke (1998) described this as a fundamental turning point in medical diagnosis and treatment, whilst Grant and Henshaw (1998) classified the Internet as the most worrying and exciting move in information provision with websites, at this time, becoming a common source of consumer health information.

Such access generated what could be said to be paternalistic attitudes amongst health professionals and the government, amid concerns over new challenging patients who brought reams of critical information into the consultation (Brooks 2001) a need was identified to try to continue to control information under the remit of quality. There was concern over information overload and whether the public was able to discern between good and bad quality information (Grant and Henshaw 1998, Richards 1998, Sheppard and Charnock 1999, Coulter 2000).

At this time, such initiatives failed to deal with issues relating to access, cost and uptake of information services. Dyke (1998) identified the problem with IT literacy; that people using the NHS were disproportionately in the older age groups and were not particularly IT literate. Furthermore, the level of IT literacy of minority groups did not seem adequately assessed. Dobson-Mouawad (2000:160) suggested that it was not a 'panacea' and it often excluded those very communities who needed consulting the most. Richards (1998) questioned whether increased information giving promotes self-help or just put more demands on stretched resources. Did it increase effective use of limited services or increase demand from the articulate minority.

4.9 Compacts & Regulation

The 1990s also saw the development of local compacts, which heralded a new relationship between the state and the voluntary sector (Halfpenny and Reid 2002). . The voluntary sector, although advocating a stronger decision-making role within new proposals (Jones et al 2004) would also have to answer calls for greater transparency and accountability (Miller 2002). Indeed, the increasing number of charities at this time again led to increasing demands for greater accountability and regulation in the form of increased centralised control (Craig et al 2004). Furthermore, Craig et al (2002) cited in Craig et al (2004) research into local compacts revealed continuing marginalisation of black and minority ethnic groups and a voluntary role that was narrowly and contractually defined. Milewa (2002b) and Miller (2002) asserted that such imposed partnership and contractual arrangements were shaping public involvement and linked the policy directives to strategies of surveillance and accountability. Craig et al (2004) also warned of the difficulties of internalising the voluntary sector within the health system leaving it more accessible to government control.

4.10 Scandals, Crisis & The Kennedy Report

Scandals and crisis within the health service were prominent within this period of policy making. These included infant deaths following heart surgery, organ retention and a GP serial killer, culminating in publication of the Shipman Inquiry (see Shipman Inquiry 2002, Shipman Inquiry 2004) as well as a winter bed crisis and hospital closures (Shapiro 2000). The scandals served to undermine public opinion in the service and questioned medical professionals' ability to self regulate (Klein 1998, Hogg and Williamson 2001). The resulting Final Report of the Public Inquiry into children's heart surgery at the Bristol Royal Infirmary (1984 – 1995) – the Kennedy Report (2001) and government reaction was to radically impact how public involvement was to develop within primary care, with a number of central directives identified in publications such as 'The NHS Plan' (DoH 2000).

The Kennedy Report, itself, featured 198 recommendations (Collins 2001) and emphasised the need for honesty and respect within the patient and professional relationship. Importantly the report identified continuing flaws and failures within NHS culture and organisation (Kennedy Report 2001). It advocated that service needs

should be designed around patients needs, with the emphasis on partnership. However, the strongest discourse focused on regulation for both managers and health professionals, strongly linked to quality and patient safety, with compulsory clinical audit. Public involvement was redefined as empowerment (Kennedy Report 2001).

4.11 Policymaking in the 21st Century – Modernisation or Surveillance

Within PCGs early development, the government launched a 'National Listening Exercise', collecting views from NHS staff and the public on services. Much of this consultation assisted in the development of the NHS Plan (2000). Chapter 10 of the NHS Plan related directly to patient and public involvement with strong emphasis on terms such as protection, advocacy, scrutiny and redress (DoH 2000) reflecting the impact of medical scandals, whilst still championing choice. The document also reflected a number of continuing government themes, particularly in relation to increasing patient information, encouraging self-care, freedom of information and developing information technology. The establishment of the Appointments Commission was also heralded, with the Commission taking over the statutory duty of appointing chairs and non-executive directors to all local NHS boards in April 2001. Adopting an equal opportunities policy it would be accountable to the Secretary of State and the Office of the Commissioner for Public Appointments (OCPA) (see Chapter Seven for further discussion).

By 2001, doctors would participate in compulsory annual appraisal and clinical audit (Rowe and Shepherd 2002) and the power to remove or suspend GPs devolved to health authorities. There were attempts at addressing issues of self-regulation (Hogg and Williamson, 2001), with new regulatory bodies as well as a reformed GMC and the establishment of the Council for the Regulation of Health Professionals (DoH 2000, Rowe and Shepherd 2002). However, the establishment of PALS, Patient Forums and the suggested abolition of the Community Health Councils had the potential to make the biggest impact on PCGs/PCTs and public involvement.

A NHS-wide Patient Advocacy Liaison Service (PALS) was to be established in every Trust by April 2002. Within the document there was a clear definition of the potential functions of these groups, these included: -

- Information provision to patients and carers

- Problem solving at an early stage
- Intermediary between people and specialist advocacy services
- Resource for information and feedback for Trusts and Patients Forum (DoH 2000:7)

PALS would be expected to operate within a local network and across boundaries, providing an 'early warning system' (DoH 2000:7). However, the NHS Plan (2000) reflected a strong emphasis on hospital services with no detailed suggestion of how this would be operationalised within a primary care setting. Baggott (2005) provides an evaluation of this new system, which became operational in 2003. Although taking on some of the functions of CHCs (Milewa 2004), the re-named Patient Advice and Liaisons Services were not independent and Baggott (2005) suggests that their implementation was confused and haphazard. These organisations had an unclear relationship with advocacy bodies, had accessibility issues and were disconnected from the systems of clinical governance (Baggott 2005). PALS did not have the resources to challenge bad practice or poor services (Baggott 2005) and remained internal to the service. Another organisation - the Independent Complaints Advisory Services (ICAS) was commissioned at a national level, however Baggott (2005) asserted that it had limited powers.

Interestingly, the NHS Plan (2000) heralded the re-emergence of the local authority in scrutinising the NHS, seen as 'an important democratically elected tier of government' (DoH 2000:94). This followed years of disempowerment, particularly in the 1940s and 1970s (see Chapter One). The document identified that chief executives of NHS organisations would be required to attend the main local authority scrutinising all-party committee at least twice annually if requested. However, government policy remained consistent in its treatment of Community Health Councils by heralding the demise of these organisations (Hogg 1999) with arguments focusing on the lack of democratic credentials (DoH 2000).

Overall the NHS Plan had a strongly reactive undercurrent. Examples of citizen involvement were visible, but the focus was on scrutiny rather than participation, potentially a by-product of the ensuing scandals and crisis evident in the late 1990s. Involvement could be seen pervading almost all NHS bodies e.g., a third of the

members of the new NHS Modernisation Board would be citizen and patient representatives as would be one-third of the membership of the new Reconfiguration Panels (DoH 2000, Calnan and Gabe 2001, Rowe and Shepherd 2002). Again, the CHI would include citizen and lay inspectors on all review teams (Calnan and Gabe 2001, Rowe and Shepherd 2002) and a new Citizens' Council would be established to advise NICE on its clinical assessments (DoH 2000). The document heralded this as 'a package of radical reform' (2000:95), however the language is tentative, with more 'could' and 'if' than 'will' and 'should'. The emphasis on public surveillance of professionals tended to negate the ability to actively participate and share responsibility.

'Shifting the Balance of Power within the NHS' (DoH 2001a) continued to reflect a strong emphasis on health professionals. Part of shifting power was related to moving power and resources in the NHS to frontline staff, who understood the needs and concerns of patients (DoH, 2001a) and was re-iterative to government rhetoric in 1997. However, the Health and Social Care Act (2001b) was the document that redefined public involvement as enforced, dedicated scrutiny and included: -

BOX 28

New Public Involvement Initiatives

- New powers for local government Overview and Scrutiny Committees (OSCs) to scrutinise
- A new duty on the NHS to involve the public in the planning and development of services, and in major decisions
- A new duty on the Secretary of State to make independent advocacy services available to people wishing to make a complaint against the NHS (DoH 2001b:6)

The development of OSCs meant democratically elected bodies would now be able to scrutinise the NHS with effect from 2002. Baggott (2005) described the committees as having a weak form of accountability, with many different approaches to their development (Coleman and Glendinning 2004). The Act again placed a new duty on the NHS to involve the public in decision-making, but, this was not to be prescriptive and yet another toolkit was suggested (Rowe and Shepherd 2002).

Each Strategic Health Authority would also have citizen involvement (DoH 2000). At this level of involvement there was a stronger emphasis on social inclusion and community development, with health authorities supporting and co-ordinating community involvement within the area (DoH 2001b).

BOX 29

Independent Local Advisory Forum – Suggested Functions

- To advise on local health priorities
- To contribute to the development of the HimP (DoH 2000:94)

Also a Citizens' Council was established to advise NICE on values related to decision-making and guidance on treatment (DoH 2000) with the first meeting held in 2002, with the Council's operation paralleling that of a Citizen's Jury.

The discussion document 'Involving Patients and the Public In Healthcare' released in September 2001 was again strongly influenced by the Kennedy inquiry and the emphasis within the document is on 'systemic involvement' (DoH, 2001c:5). Interestingly, it described patient and carer campaigns outside of the system as an 'out-dated model' (DoH, 2001c:5) and, again, highlights attempts at centralised control. However, its rhetoric remained re-iterative and is found in many of the previous policy directives (see Chapter One & Two). For example mechanisms for involvement should be evaluated, the public should have access to training and funding to allow full participation, the need for a wide range of individuals to be involved. The document also signalled yet another discussion period (DoH 2001c:4) following reactions to the proposed abolition of CHC's. Baggott (2005) identified a rigorous campaign surrounding the abolition had led to a number of concessions, particularly the development of a national body relating to public involvement called the Commission for Patient and Public Involvement in Health (CPPIH) (see National

Health Service (NHS) Reform and Health Care Professions Bill (2002), Rowe and Sherpherd 2002 and Baggott 2005).

Milewa (2004) described the CPPIH as a quasi-independent national body; with a 16 million pound budget it was operationalised in January 2003. Its functions emphasised a co-ordinating role (Rowe and Shepherd 2002); it was to give advice regarding public involvement and consultation; its role with Patients Forums was one of support as well as assisting with the development of standards and giving advice on advocacy (DoH 2001c:29). Although the organisation was envisaged as an independent non-departmental public body (DoH 2000), the organisation's work programme was to be agreed by the Secretary of State, who had the power of veto (Baggott 2005). Again, this identified a continuing need for centralised control and may also have reflected concerns over the politicisation of health issues linked to the organisation's predecessors. Very quickly the organisation's effectiveness was being challenged (Health Committee 2003). Despite setting up 572 forums by December 2003, Baggott (2005) suggested that it failed to build support and was recommended for abolition.

Patient Forums, like the CPPIH, reflected functions that had previously fallen under the remit of CHCs. Forums were to monitor and review services and obtain views from patients and carers on those services as well as providing advice, reports and recommendations (DoH 2002:26). Their function also incorporated the inspection of premises and the production of an annual report (DoH 2002:26). The forums finally became operational in December 2003 and had been re-named as Patient and Public Involvement Forums (PPI Forums) – PCT PPI Forums were made up of local residents (Baggott 2005). However, a number of difficulties were identified. Members were still appointed and largely advisory (Milewa 2004) and again they had little more democratic legitimacy than CHCs (Baggott 2005). Baggott (2005) also identified that 11% of forum members resigned after the first six months. This may have been due to fragmented support as such support was outsourced to local voluntary organisations, who often lacked adequate experience in this field (Baggott 2005).

Again, another consultation exercise commenced in October 2005. This strategic review of patient and public involvement consisted of a series of discussions with

forum members, public and voluntary sector stakeholders and included an on-line survey by MORI. However, the consultation was criticised for a restrictive timetable (consultation period 10th to 24th October 2005) and the inherent problems with on-line consultation were already identified (Delap 1997, Dyke 1998). Results were fed into the White Paper 'Our health, our care, our say: a new direction for community services' (DoH 2006) with Chapter Seven dealing with public empowerment. The abolition of the CPPIH and reforms to forums were deferred to 2007, however, the suggested replacement for CPPIH - a Patient and Public Involvement Resource Centre (Milewa 2004) was put out to tender in 2005.

Finally, within this review, Foundation Trusts were heralded in the Health and Social Care (Community Health and Social Care) Act (DoH 2003). The trusts would have more autonomy operationally and were seen as a way of drawing people into a type of community membership with rights to participate in elections for governing boards (Baggott 2005). However, the Health Committee (2003:12) identified a number of concerns. The establishment of Foundation Trusts would mean that a forum would not be directly serving these new organisations. Importantly, the Health Committee (2003:12) identified two divergent and confusing policies on public involvement, with the advent of two parallel but entirely different systems within the NHS – forums & governing boards. Furthermore, governing boards were still advisory in nature with limited power and still subject to national regulatory structures (Baggott 2005). Despite these comments there were 32 Foundation Trusts in operation in England by 2006. Rowe and Bond (2003:30) described the trusts as public interest companies, which could be interpreted as a retreat from centralism. However the board of governors still functioned within a regulatory framework and research identified continuing problems with information deficit and lack of legitimacy in relation to medical knowledge, which tended to exclude lay participation from decision-making (Rowe and Bond 2003).

Summary

In analysing government policy (DoH 1997, DoH 1998a, DoH 1998b), health service circular requirements (HSC 065 1998, HSC 139 1998) and early reports (Arora and Gillam 1999, Audit Commission 2000) there seems conflicting evidence regarding

professional and government commitment to public involvement. There was a strong message that it should be an integral part of PCG activities, however this was left to local discretion with no explicit timeframe. Health professionals dominated PCG governing boards (HSC 139 1998) with little experience in the strategic planning of public involvement initiatives (Chambers 2000). However, policy making was re-routed from the fallout of public scandals and resulting damning reports. This was to have a major affect on the central definition and operationalisation of public involvement with new national involvement vehicles being advocated (DoH 2000).

However, in reviewing the new system of involvement it seems to reveal the same inherent problems of previous centrally constructed involvement initiatives, with their wings immediately clipped, taking on a predominantly advisory role with no power to inflict change and lacking democratic accountability (Milewa 2004, Baggott 2005). Familiarly, Baggott (2005:535) identifies the new system as under resourced, lacking capacity, complex and fragmented. The seventh report of the Health Committee (2003:3) in reviewing patient and public involvement also identified the new structure as a major cause for concern. Furthermore, Milewa (2004) asserted that the new involvement architecture told us little about their potential impact upon patterns of power and influence at a local level. Importantly, Crowley et al (2002:312) suggest that the NHS Reforms in Health Care Professions Bill (2001) was a move back towards a more consumerist model of participation. Rowe and Shepherd (2002) also emphasis this view, linking involvement to service responsiveness and local ownership, with the public acting as a sounding board mirroring market research in the private sector. Yet again the emphasis is primarily on information giving and feedback, taking us back to discussions highlighted in the historical perspective.

CHAPTER FIVE

METHODS

5.1 Research Question & Objectives

The purpose of the study was to develop an understanding of how health policy was interpreted and implemented within a new NHS organisational structure. The findings from the literature review and policy analysis were reflected in the development of the research question and six main objectives. The research question was stated as 'How is public involvement defined and operationalised within Primary Care Groups'. Specific research objectives were identified as: -

- To provide a demographic profile of lay members serving as members on the governing boards of PCGs.
- To document and analyse the experiences of lay members on the governing boards of PCGs.
- To explore the developing role of the lay member.
- To explore the concept of public involvement utilising professional and lay perspectives.
- To identify and assess methods of public involvement initiated by PCG governing boards.
- To describe the development and implementation of the PCG public involvement strategy.

5.2 Research Design

The design incorporated four distinct phases; three exploratory phases, which included case studies, national survey and telephone interviews and a final explanatory phase utilising a conceptual framework. The research reflected a multi-method strategy and combined both qualitative and quantitative approaches in addressing the research question (see Figure 5). The following methods and data collection tools were incorporated: -

- Case Study – Two Primary Care Groups were selected as part of a two-year longitudinal study, running from October 1999 to October 2001, data collection tools incorporated observation, interviews and documentary analysis.

- National Survey – a postal self-administered questionnaire sent to lay members on PCG governing boards in England (n=481).
- Structured, semi-structured and open interviews – conducted via telephone, with 13% of questionnaire informants (n=44).
- Conceptual Framework – Foucault's concepts of governmentality and discipline were utilised as an explanatory framework in analysing selected data from exploratory phases, focusing on emerging themes of power.

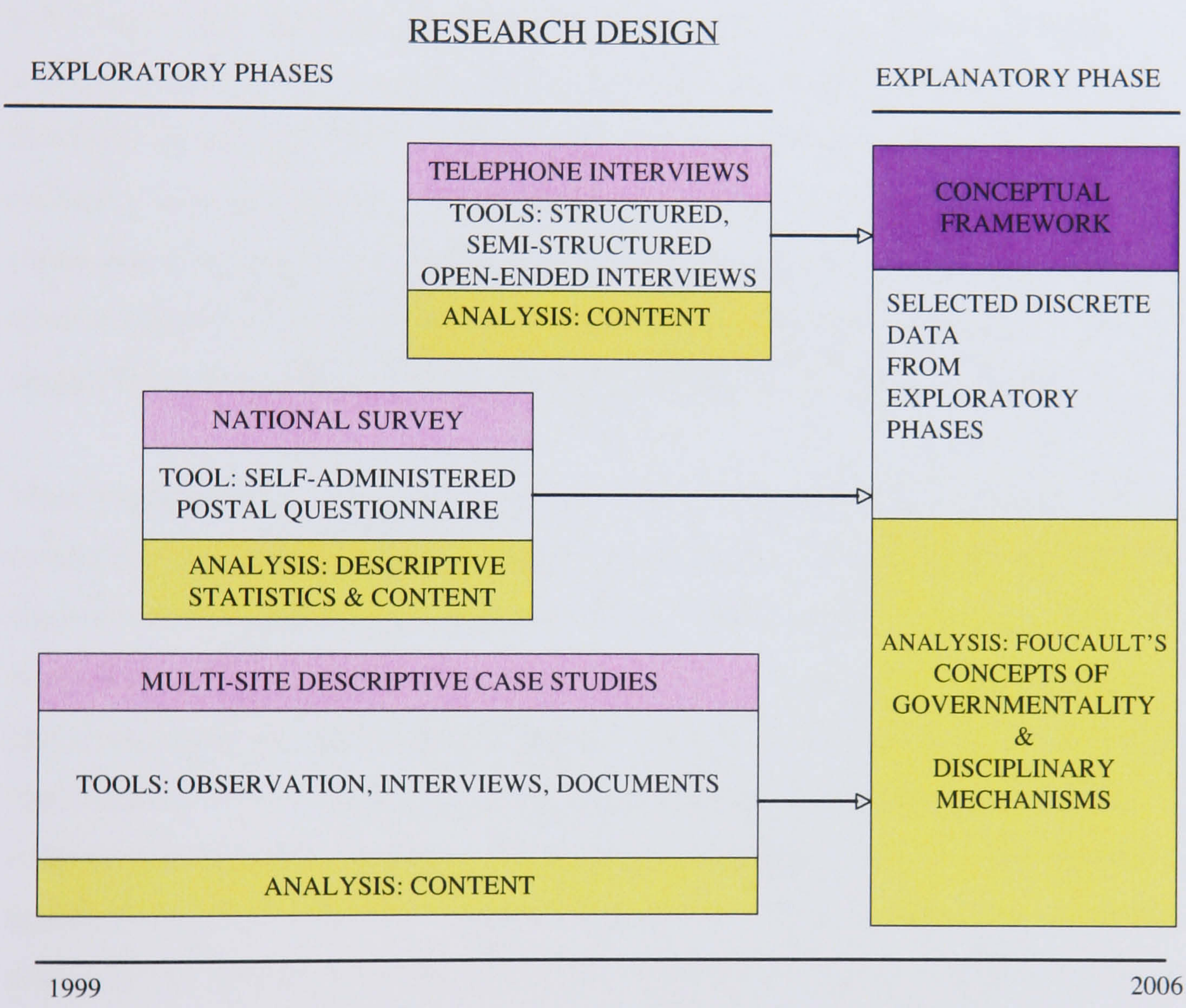

Figure 5: Research Design

5.3 Research Dichotomy

The incorporation of a mixed methods approach involved accessing a long-standing debate as qualitative and quantitative methodologies have been viewed as being essentially different and set within different paradigms (Grbich 1999). Such differences relate to the development of knowledge and the research process (Brannen 1992), with the two approaches operating at different levels of analysis and discourse (Brymen 1992). Grbich (1999:8) identifies the belief, by some theorists, that the

paradigms are antithetical: so functionally different they should never be combined, whilst others argue that any distinction is limited (Hammersley 1992) or false (Layder 1993).

Strauss and Corbin (1998) warn of the difficulties in taking a dogmatic view towards the paradigms, with Yin (1993) arguing that qualitative and quantitative methods can become mere caricatures. In reality there is wide variation, which cannot be incorporated into just two frameworks (Hammersley 1992). Furthermore, Grbich (1999) identifies the changing relationship between paradigms, moving through conflict, détente to co-operation. Such changes are also reflected in the health field, Darlington and Scott (2002) highlight a strong emphasis on empiricist approaches in relation to resource scarcity, effectiveness and efficiency drives, combined with the expansion of post-modernist traditions and resurgent interest in qualitative research. Such changes, enables the practitioner researcher (see Section 5.4) access to a wide range of qualitative and quantitative modes of enquiry (Darlington and Scott, 2002).

More important to this thesis is the debate on how the approaches should be combined, with specific reference to theoretical reasoning. Strauss and Corbin (1998) suggest combining approaches can be done for a number of reasons, two highly debated motives are integration and complementary (Layder 1993). This research project interpreted a multi-method approach as complementary as the research design identified six separate objectives. The most appropriate methods were selected to address each objective, therefore, providing complementary data sets with specific qualities (Yin 1993). Another important aspect to the study was to present different aspects of the research topic (Brannen 1992) and a multi-method approach facilitates both macro and micro levels of enquiry (Fielding and Fielding 1986, Bryman 1992, Layder 1993). Finally such an approach has been successful in studying the implementation of policy (see Bird 1992, Bullock et al 1992, Qureshi 1992).

5.3.1 Issues of Triangulation

Another area of debate focuses on the relationship between the multi-method, triangulation and enhanced validity. Miller et al (2002) simplistically highlight that quantitative approaches are good at answering when, how, what and where, qualitative approaches answering 'the why', with triangulated research design

becoming common. This research reflects 'sequential triangulation' (Grbich 1999:18), which involved alternating qualitative and quantitative data sets. Arksey and Knight (1999) describe this as between-method triangulation, where two or more distinct methods are used to measure the same phenomena. However, the issue of triangulation is not without its difficulties. Fielding and Fielding (1986) warn that triangulation does not necessarily reduce bias or increase validity, with a number of problems identified.

Both Fielding and Fielding (1986) and Brannen (1992) suggest that the multi-method approach cannot produce a single, unitary objective view of the truth. Indeed, Hammersley (1992) suggests that some methods may not be comparable and Fielding and Fielding (1986:31) maintain that each information-gathering tool is ' … privileged and constrained by its own particular structure and location'. Brymen (1988) also identifies difficulties in dealing with incongruent findings, which can be generated by the multi-method approach. Within his research review he identified that such findings were not always addressed leading to researchers deciding which accounts were correct, with too strong an emphasis on points of similarity (Brymen 1988). Researchers often link points of similarity to increased validity.

A number of suggestions are put forward to address such difficulties. Hammersley (1992) and Fielding and Fielding (1986) suggest that incongruent findings should be treated as new lines of inquiry, although this can be constrained by money and time. Bird (1992), Brannen (1992), Fielding and Fielding (1992) suggest that the multi-method approach demands that the researcher specifies the particular aims of each method within the research design and that s/he adheres to an underlying rationale. This issue is addressed in subsequent sections where methods are linked to specific objectives and their use is rationalised.

Although, Brannen (1992:14) resists equating a multi-method approach with the enhancement of validity, Grbich (1999) acknowledges that combining different perspectives can establish a more inclusive picture of the phenomenon. Stake (1998:97) adds to this discussion suggesting that triangulation is 'a process of using multiple perceptions to clarify meaning', here, triangulation helps completeness (Arksey and Knight, 1999). Fielding and Fielding (1986:33) also develop such

arguments, suggesting that triangulation is not about accuracy but depth and breadth within the study and identify the concept of 'syntheticism'. This involves fitting approaches together, which adds to the plausibility of the researcher's interpretation. This discussion reflected the aim of this research study, which was to provide a detailed description of the phenomena rather than gaining enhanced validity.

5.4 Role of the Researcher

Throughout the research I viewed my role as a reflexive researcher practitioner - Edwards and Talbot (1999) suggest research is a creative activity and in relation to practitioners, it is seen as supporting and developing professional knowledge bases (Reed and Procter 1995). Reed and Procter (1995) also identify a differing relationship to the research field, with practitioners often having a greater familiarity than external researchers. Reflexivity is also seen as a crucial aspect of this role (Cheek 2000). Reed and Procter (1995) are highly critical of depersonalised research, emphasising the influence of social and political issues. Cheek (2000) suggests that reflexivity brings into examination the concept of the research field, as it is constructed via data collection. Reflection on role and process also addresses issues of reliability and validity as it makes '… the research process transparent, being explicit about what was done and why' (Arksey and Knight 1999:56).

An important aspect of such reflection is to address personal issues such as background, personality, attitudes and actions, which have contributed to the process (Arksey and Knight 1999). Thompson (1995) echoes this viewpoint, suggesting that social location influences our perceptions and responses and advocates a critical reflexivity approach – this meant reflecting on my own professional profile. As an experienced nurse and community tutor, I had an established working relationship with key professional personnel within primary and community care and an awareness of NHS culture. However, contact with lay members, non-executive directors, the wider voluntary sector and the public had been minimal. One of the main motivations as a practitioner was to place the importance of such involvement within my practice as a clinician and educator.

Another important issue related to reflection focused on addressing emergent emotional issues during data collection and analysis. Hallowell et al (2005:2) identify

the 'reflexive turn' in research report writing, arguing against the provision of 'sanitised accounts' of the research process and suggesting that with each project there is emotional work. Such emotional issues related to knowledge and values as a professional, which had the potential to impact on the research (Reed 1995). At times, emotional reactions related to the level of anger and frustration focused on health professionals and NHS managers by citizens within public arenas and perceived hostility towards professionals by some voluntary and development workers. Juxtaposition was my own anger and embarrassment when informants related incidents of unprofessional behaviour or these were directly observed. Such emotional involvement can lead to research difficulties (Polit and Hungler, 1997) and Reed (1995) advocates a contemplative response, questioning one's own assumptions. I became more aware of my own professional values throughout the active research period particularly in relation to the public/professional interface and the need to handle such revelations empathetically (Hallowell et al 2005).

5.5 Case Studies

Although government guidelines provided a general framework for public involvement, with two dictates regarding strategy and lay membership (see HSC 139: 1998), no specific objectives or time frame were identified. Indeed, health policy relinquished responsibility for its implementation to each PCG. Potentially, public involvement could have been developed very differently, offering a wide range of possibilities and diversity between groups. It was clear that such a phenomenon was context-dependent, suggesting the choice of case study method for further investigation. As Yin (1993) suggests, the method is most suitable when there is a requirement to cover contextual conditions. The case study is also seen as highly adaptable (Yin 1993, Robson 2002) and can be allied to a multiple method approach to data collection (Robson 2002). It can also be the choice of research tool when assessing policy implementation and studying organisations (Robson 2002, Bird 1992) an important aspect to this study.

However, as Gbrich (1999:190) identifies case studies are a somewhat 'contentious entity'. Both Robson (2002) and Stake (1998) highlight the main difficulty, the question of what constitutes a 'case study' as almost anything can be seen as a 'case' (Robson 2002, Gbrich 1999). Its ambiguous use has led, at times, to the method been

seen as a 'soft option', often utilised as a forerunner or as complementary (Robson 2002:179). Robson (2002) asserts that Yin has done much to resuscitate the case study as a serious option in social research. Yin's (1993) approach urges the emulation of a scientific method to improve the quality of the research. Quality was an important issue, therefore, this research utilised Yin's case study design approach and it gave a number of other advantages.

Particularly persuasive was the detailed attention given to all aspects of design, Yin's (1993) description of the unit of analysis, case selection, screening criteria and descriptive scenario were well suited to developing and operationalising specific research objectives of this thesis. Yin (1993) identifies six different types of case studies: - descriptive, explanatory and exploratory, each can be either a single or multiple study. Similarities can be seen in Stake's (1998) identification of intrinsic, instrumental and collective studies, however, Yin's work is, perhaps, more detailed and gives greater diversity of contexts and usages (educational partnerships, information system, youth programs, health prevention).

This piece of research was a multi-site, descriptive case study. Such descriptive studies are often associated with research questions and objectives rather than a hypothesis (Carter 1991). The descriptive study was also chosen as it focused on the existing situation and associated beliefs (Carter 1991), this was particularly crucial as the research focused on the implementation of an aspect of health policy in a newly developing NHS organisation. Multi-site case study research also involves the comparison and contrast of different locations (Grbich 1999), with Yin (1993:5) suggesting that such sites should be selected so they are replicating each other, either as direct or systematic replications. However, Schofield (1993) warns against the use of large numbers of sites in attempts to gain generalisability, suggesting such large numbers undermines the depth of understanding of individual sites, which is the hallmark of a qualitative approach. Depth of understanding, again, was important to this study and only two sites were involved, there were also the practical issues of time and distance related to a single-handed researcher to consider (Grbich 1999).

Yin (1993) suggests that investigations, which primarily focus on description call for theory to determine the priorities for data collection. This establishes the boundaries

of the project and aids research design and the generalisation of subsequent results (Yin 1993). Yin (1993) in this context, views the descriptive theory evolving from literature and policy review, such a review also aids the development of the unit of analysis. The unit of analysis helps to develop the boundaries of the study and therefore, defining the unit is crucial to the researcher (Yin 1993, Stake 2000). Government policy and literature review provided the theoretical background in the formation of this definition.

5.5.1 Unit of Analysis

The unit of analysis focused on the governing board of the Primary Care Group, the main decision-making vehicle, it was this body that would be responsible for the public involvement strategy (HSC 139:1998). Within this unit of analysis 'embedded units' (Yin 1993:48) were identified as the research developed such as the public involvement subcommittees, stakeholder conferences etc. Particular emphasis was placed on events, situations, vehicles where 'members of the public' could potentially become involved (see Introduction regarding the demarcation between patient and public involvement). Such embedded units, however, were seen as part of the main unit of analysis, as they were board initiated.

5.5.2 Case Study Selection & Screening Criteria

There are several different rationales regarding case study selection (Yin 1993). Schofield (1993:99) identifies three domains, which focus on typical, leading edge and flagship sites. Typical sites are chosen on the basis that they fit within a typical situation, where as, leading edge sites usually form test sites and flagship sites are chosen for special circumstances with findings linked to special characteristics (Schofield 1993). However, Fielding and Fielding (1986) suggest that two main sources of bias in fieldwork are to select field data from ideal or unusual sites. This research focused on two sites that were defined as typical, such a definition was linked to certain PCG characteristics, which formed part of the screening criteria.

The screening criteria were linked to typical board structure i.e., GP Chair, majority of GP board members, with one lay member, the other criteria, related to the operational level of the PCG. Both case studies needed to be operating at Level 2. This was again typical of the majority of PCGs and gave the board some budgetary

independence. However, convenience was also important, as both sites had to be within easy travelling distance. My knowledge as a practitioner certainly aided the selection and access to PCG sites, both through a combination of general knowledge of general practice/NHS Trusts and specific knowledge about the setting, in this case, primary care (Reed 1995).

Access to sites needs to be negotiated with gatekeepers, such as people in authority (Grbich 1999, Burgess 1984). In Case Study A – the Chair and lay member of the governing board were approached separately and informally and were interviewed regarding their experiences. The possibility of using the PCG as a case study was suggested at this time and accepted in principle. A formal letter requesting access with an outline of the research proposal and benefits of the research were sent to the Chief Executive and access was gained in October 1999 (Appendix Two – Research Proposal). However, approaches used to gain access hold implications for the research, researcher and research process (Burgess 1984). Within Case Study A there was some pressure to become involved in personal projects or literature searches and I had to make it clear that I was unable to take on extra activities, but suggested that I was willing to share findings with the PCG. Key personnel in Case Study B already had established connections with the Centre for Primary Care Research, collaborating on a PMS pilot. I was invited to a meeting with the Chief Executive and lay member, where I outlined my research interest and I was asked to review a draft paper by the health authority on public involvement. A formal letter requesting access was also sent and again access to the site was gained in October 1999.

5.5.3 Data Collection Tools

The primary methods of participant observation, unstructured interviews and documentary evidence (Marshall and Rossman 1999) were utilised within the case studies. Yin (1993) asserts that the depth within the study requires multiple sources of evidence rather than a single data collection tool. Multiple sources of evidence are also linked to triangulation, with Yin (1993) suggesting greater confidence in results, if interviews, documents and observations all point to the same direction. Fielding and Fielding (1986) also emphasise the importance of triangulation to counteract threats to validity but highlight that differences as well as similarities are significant. Such differences became important within this study. Multiple sources where used for

cross-examining of accounts (Douglas, 1976 cited in Grbich 1999) and it soon became clear that some views relating to public involvement were incongruent with actions (see Chapter Seven) and became areas for further exploration (see Section 5.3 for further discussion on issues of triangulation).

5.5.3.1 Observation

This data collection tool was essential to the research strategy as Polit and Hungler (1997) highlight its strength is the diversity of data collection it facilitates. Particularly important is its ability to provide an insider perspective (Grbich 1999). Specific research objectives were linked to the case study (see objectives 5 & 6, Section 5.1) and assisted in the focus of the observation as well as the development of a descriptive scenario (Yin 1993) with an emphasis on citizen involvement. The observation was unstructured and overt. At meetings I ensured that I was introduced as a researcher and at events I wore an identification badge. However, it was possible whilst observing large processes such as conferences that all participants were not aware of my status, however, all were within public arenas. Observation focused on events and initiatives where the public as citizens would have access and an opportunity to participate. The observation took on a critical public perspective - focusing on physical environment (venue, access), type and level of involvement, personnel involved, topics of discussion. Multiple rather than mobile positioning (Polit and Hungler, 1997) was utilised within the two sites and a number of different locations such as town halls, civic centres, village halls, health centres/surgeries, hospitals, PCG headquarters were incorporated. Grbich (1999:128) suggests that limited observations periods are more usual and used in settings that have a lot of continuous activity. This reflected my own situation and on average visits to the case sites were fortnightly, for 3 to 4 hours at a time.

My level of participation needed to be decided early on (Grbich 1999), particularly as the case studies were accessed only six months after commencing the thesis. Gans (1982) cited in Crbich (1999) suggests three possible researcher roles – total participant, participant-researcher/researcher participant and total researcher. Within this description I acted mainly as a total researcher. Although I had an established theoretical knowledge of public involvement I had no practical experience and did not want to be perceived as an expert. My aim was to observe and document how public

involvement developed without my deliberate interventions and their potential to affect outcomes. In this capacity the researcher is physically separate, only visiting the setting on regular occasions for limited periods, with observation as the sole purpose of the visits (Gans 1982 in Grbich 1999). Much of my time on site was in this role, however, the drawback to this approach potentially can be seen in the discussion of Case Study B (see Section 5.10), if I had been perceived more as a participant would I have been able to access more initiatives? However, levels of involvement did fluctuate. I was asked to review documents and participated in a number of workshops relating to PCT visioning. Also I was a group member of public involvement subcommittees and was identified as such within the minutes.

5.5.3.2 Field Notes

Accessing the site relatively quickly generated some concerns regarding field notes, which focused on the ability to pick up salient features from each observational episode as well as an appropriate mode for analysis. Practical suggestions regarding the use of wide margins (Grbich 1999, Burgess 1984) proved particularly useful in facilitating effective analysis. Equally, differentiating different aspects of the notes improved the efficiency and depth of analysis. Guided by Polit and Hungler (1997) field notes were categorised as theoretical (interpretative attempts to attach meaning to observations), methodological (instructions or reminders about how subsequent observations will be made) and personal (comments about the researcher's own feelings during the research process).

5.5.3.3 Documentary Analysis

The type of documentation examined within the case studies included: - minutes of meetings, agendas (public involvement subcommittees, board meetings) three-year plans, reports on public involvement initiatives, strategy documentation, consultation documents, leaflets, newsletters and all were in written form. I would have liked the opportunity to review and analyse websites, however neither case study had completed this work before leaving the fieldwork area. Such analysis acted as an essential comparative tool (Grbich 1999, Bowling 1997) both to the field data, but particularly to the testimonies given within unstructured interviews. Documentary analysis also provided a useful historical backdrop, as I was able to track the

development of the public involvement strategy utilising draft documents from shadow PCGs in 1998/99.

As the case studies progressed, a major challenge was the effective organisation of large amounts of data. Documents were re-organised into different modes of public involvement e.g. public consultation for Trust status, patient participation groups etc. With a number of different methods for data extraction available (Bowling 1997) the decision was made to focus on how, when and where public involvement was discussed within these documents. The analysis should address issues such as authenticity, reliability, meaning and theorisation (McCulloch 2004). The authenticity of the documents did not prove problematic as their provenance had been established. More interesting to this research were issues of reliability. Such reliability relates to the accuracy of the account and issues of bias (McCulloch 2004). Some of these issues were observed e.g., 2 reports on the achievements of a public participation subgroup. One reporter had not been present at any of the meetings, the other produced little evidence in relation to effectiveness, although, was able to present a feel good factor (see Chapter Seven).

Furthermore, McCulloch (2004) identifies an increasing emphasis on the nature of the document itself as a text. Bowling (1997) suggests that such texts can be seen as social constructions of reality and emphasises that the process of construction is as important as the content. McCulloch (2004) advocates the use of a theoretical framework to add the interpretation of documents and links this to elements of meaning and theorisation. Such issues were addressed within the study as the data was analysed using content analysis, but also Foucault's concepts of governmentality and discipline.

5.5.3.4 Interviews

The case study included qualitative interviews. This was felt as the most appropriate method as the aim was to gain an understanding of the knowledge, experiences and feelings of interviewees in relation to public involvement (Britten 2000, Rubin and Rubin 1995). Such interviews also supported other data collection tools within the study. For example, related tapes and transcripts can eliminate problems of the accuracy of field notes (Silverman, 1997). Britten (2000:15), in discussing the

interview technique, suggests that ' ... clinicians may feel that they already possess the necessary skills, and indeed many are transferable'.

However, my first few attempts were highly structured neglecting the fact that such an approach is not usually utilised within the described context (Robson 2002). I also should have been more prepared for the organisational environment. In a newly developing organisation, space was at a premium and it was difficult to find a quiet environment for in-depth interviews and I had first hand experience of related pitfalls (Britten 2000) - particularly interruptions and distractions. The hectic schedules of interviewees also proved difficult to manage, especially timetabling interviews. It became clear that I had to rethink my interview strategy and develop some much-needed flexibility, which highlights the importance of monitoring interview technique (Britten 2000).

I developed a more conversational style to interviewing and much has been written regarding interviews as conversations. Burgess (1984:102) emphasises the use of interviews as conversation, suggesting that unstructured interviews are 'conversation with a purpose'. However, such interviews differ from ordinary conversations as they provide information for analysis and dissemination. They are guided by the researcher (Rubin and Rubin 1995) and can be described as professional conversations (Kvale 1996). Also such conversations are not an equal partnership, the researcher still defines and controls the medium (Kvale 1996, Keats 2000).

Keats (2000) highlights that a particular individual or group of informants determines not only the content but also the style of interview. As stated, informants had hectic timetables and I found willingness to be interviewed increased considerably when strict 10 to 15 minutes time limits were offered to the informant. Furthermore, some informants were more accessible by telephone, some accepted tape recording of interviews others did not. However, such an informal approach still reflected structure and purpose (Kvale 1996). Preparation for such sessions became crucial (Wengrat 2001) to ensure the right questions were incorporated (Rubin and Rubin 1995, Britten 2000). Importantly, these brief interviews were much more likely to facilitate follow-up interviews (Rubin and Rubin 1995). Addressing the technological difficulties with

telephone interviews also assisted in the efficient collection of data. Taped interviews were transcribed and subjected to content analysis (see Section 5.8 for discussion).

5.5.4 Issues of Generalisability

Generalisability is a main area of contention in qualitative studies and the case study is no exception. Some authors such as Lincoln and Guba (2000) discard the idea of generalisation emphasising replacement concepts such as the working hypothesis. Others such as Stake (2000) and Schofield (2000) have re-interpreted the concept putting forward the idea of naturalistic generalisation, comparability and translatability. Lincoln and Guba (2000:28) suggest generalisation 'oozes determinism' and the majority of their criticisms relate to generalisation in its classic, logical form. Re-interpretation is discarded and their approach is to replace logical generalisation with the working hypothesis, whilst introducing the concept of transferability - stating outcomes might be held for case study B which were discovered in case study A (Lincoln and Guba 2000). The degree of transferability relates to the similarity between the sending and receiving case study - the judgment is linked to knowledge of both contexts and is dependent on thick description (Lincoln and Guba 2000). However, this approach is criticised due to the amount of information required regarding the study and setting (Schofield 2000).

Stake (2000) advocates redefining generalisation, suggesting that case studies can facilitate learning for those who use them; therefore, the findings have an intrinsic value. However, in terms of this research study, public involvement was part of a national policy and finding intrinsic value was not its main purpose. Schofield (2000) practically suggests that funding is linked to studies that can provide generalisable results. She also suggests a reconceptualisation, with the general thrust of the argument lying with 'gaining generality through the synthesis of pre-existing qualitative studies' (Schofield 2000:74). Schofield (2000) introduces the concepts of comparability and translatability, the former relating to the degree results from one study can be compared to another, which focuses on how adequately components are described and defined. Translatability relates to a clear description of theoretical stance and research technique and highlights the importance of designing qualitative studies to maximise their generalisability, emphasising typicality and multi-sites (Schofield 2000).

Gomm et al (2000) criticise naturalistic generalisation and transferability, as the emphasis is placed on readers to determine whether findings are applicable. Furthermore, transferability provides no guidance about which case to study and is dependent on similarities. However, as discussed earlier, difference can be as important (Fielding and Fielding 1986). Neither does it provide a sound basis for the design or justification of case study research (Gomm et al 2000). Gomm et al (2000) maintain that generalisation can be made utilising the case study method and introduce the concepts of theoretical inference and empirical generalisation. Theoretical inference is defined as ' ... reaching conclusions about what always happens, or what happens with a given degree of probability, in a certain type of theoretically defined situation' (Gomm et al 2000:103). The research strategy is to aim 'to identify a set of relationships amongst variables that are universal' (Gomm et al 2000:104). Empirical generalisation involves '... drawing inferences about features of a larger but finite population of cases, from the study of a sample drawn from that population' (Gomm et al 2000:103).

Although these viewpoints are often presented as mutually exclusive, the review identifies a number of core themes – theoretical definition, typicality, description and time period – which aids this research in its quest to generalise its case study results. Yin (1993), Gomm et al (2000) and Schofield (2000) emphasise the importance of developing a 'theoretically defined situation' (Gomm et al 2000:104) and this had been completed through the literature and policy review. However, Gomm et al (2000) seem to have overlooked two important areas relating to theoretical definition, arguing that is uncommon for sufficient information to be provided regarding the boundaries of the studied case and collected data. They suggest that readers need to assess the validity of the internal generalisation, the emphasis here is placed on the reader, which was used to criticise both natural generalisation and transferability. However, with the use of a descriptive theory (Yin 1993) the boundaries of the case can be clearly demarcated.

Fielding and Fielding (1986), Gomm et al (2000) and Schofield (2000) highlight the importance of typicality in relation to case selection. Gomm et al (2000) link typicality to improving the accuracy of generalisations, namely, '...to consider the relevant respects in which the target population might be heterogeneous' (Gomm et al

2000:105). As discussed in Section 5.5.2 case selection focused on two typical sites. This selection was aided by the on-going development of the excel package via a government website, which provided information about the population as a whole. Furthermore, both the concepts of transferability and comparability require that case studies are adequately described, which is also supported by Yin (1993). Such description was crucial in discussing findings and making comparisons with related case studies. Finally, the time span of a case study is also linked to generalisation, which is also identified by Schofield (1993), Gomm et al (2000) and Yin (1993). Schofield (1993:104) asserts that studying a phenomena over a substantial time period, addresses one aspect of generalisability that quantitative research usually doesn't – this relates to the potential life cycle of a phenomena rather than giving just a snap shot. Although the case studies did not encompass the full life cycle of PCGs, the studies were able to reflect the impact of on-going policy directives at specific points in time (Gomm et al 2000).

5.6 National Survey

Phase Two focused on a postal self-administered questionnaire (see Appendix Three – Example of Questionnaire). The survey was seen as the most appropriate tool for a number of reasons specific to the research study. Information was required from a large number of informants (n=481) across England and the survey facilitates wide geographic coverage (Bourque and Feilder 1995). Furthermore, it is appropriate for a wide variety of subject areas (Polit and Hungler 1997) and it was designed specifically to address research objectives relating to demographic profiling and role development. It is also economic, costing 50% less than phone and 75% less than a personal interview (Bourque and Fielder 1995). Finally the postal questionnaire is less of a social encounter and, therefore, reduces difficulties with social desirability and interview bias and it enables greater anonymity (Bourque and Fielder 1995, Bowling 1997), again an important ethical aspect to the research study.

5.6.1 Sample

The sampling strategy focused on 100% of informants. Census sampling was chosen rather than random or a cross-section of the population to increase the generalisability of forthcoming results and to provide a comprehensive profile. Bowling (1997) emphasises the importance of a sample frame of addresses. I decided to create an

excel file, developed initially, from a government website giving access to the names of lay members and PCG addresses. However, there were a number of time-consuming difficulties with this development. Many PCGs had commenced operation from practice or health authority premises but had moved with the database not adequately keeping pace with this. There was also confusion relating to the lay member, in reality, the lay member turned out to be the non-executive director or a co-opted board member. This meant extra telephone work, with some reluctance to give out information by administrative staff. Therefore, the development of the file took longer than anticipated, although it highlighted the pace of organisational change. The mail merge facilities related to the excel program proved invaluable to the efficient posting of the questionnaire. The first questionnaires were posted in February 2000 (n=481) and following a second mailing the response rate was 340.

5.6.2 Development and Piloting of the Questionnaire

The content of the questionnaire was generated by literature review, discussions with lay members, Chairs and chief executives from a number of PCGs. It also made use of developing themes from the two case studies and reviews from academic supervisors, hopefully ensuring content validity (Bowling 1997). The questionnaire developed around the themes of role development and profiling and reflected in three distinct topic-based modules (Bowling 1997): -

- The Role of the Lay Member
- Personal Profile
- Occupational Profile

It included 20 questions; Q19 asked for the informants' willingness to participate in Phase Three of the research project and Q20 asked for general comments.

There were three general objectives in piloting, to check understanding and clarity, the length of time to complete and the data collection process itself (Fowler 1993, Polit and Hungler 1997, Punch 2003). The survey was tested with 10 lay members with informants contacted by telephone. They were asked to complete the draft questionnaire and a comment sheet. Telephone and E-mail addresses were given for further feedback or queries. Attempts were made to make face-to-face contacts with informants via lay member support groups or one-to-one interviews. Unfortunately this proved fruitless and highlighted how busy lay members were. However, the

impact of piloting on the development of the questionnaire can be seen within Appendix Four – Pilot Questionnaires.

The first module – the role of the lay member – developed chronologically moving from selection procedure, role development, subgroup membership, training and role allocation culminating in administrative questions placing the PCG geographically with the level of operation. Module Two focused on the personal profile including age, gender and ethnicity. Finally Module Three asked for an occupational profile including paid occupation, nature of employing organisation, employment within the NHS. It was suggested that potential sensitive topics are left to later within the questionnaire, so even if such topics are not completed, placing them late does not threaten the completion of the rest of the questionnaire (Bowling 1997). Indeed, as can be seen in Appendix Four (Pilot Questionnaires) re-drafting incorporated moving profiling to the end of the questionnaire.

Suggestions relating to identification numbers, brief introduction and issues of confidentiality (Bowling 1997) were incorporated. Instructions for informants were clearly stated, each section was introduced in bold, lower case lettering and directions were given on how to fill out questions (Bowling 1997). There were also linking sentences when moving to subsequent modules of the questionnaire. Filter questions (Q5 and Q13) were clearly labelled and caused no difficulties. Space was given for comments on specific questions. The amount of space suggested the level of detail required, as there were concerns over the amount of data generated (see Appendix Three). With some inventive word processing and margin adjustment, none of the questions and responses were split over 2 pages. The format of the questionnaire reflected a majority of closed-ended questions, however, areas where replies were unknown or potentially numerous included open-ended questions (Bowling 1997). These related to role development and group membership.

As stated, the first questionnaires were distributed in February 2000 (n=481). Each was coded for data analysis and included a covering letter and pre-paid envelope (see Appendix Five – Covering Letter 1). The covering letter is a method for increasing the response rate (Bowling 1997). The aims of the research and issues of confidentiality were incorporated and the letter was presented on headed notepaper to

increase legitimacy (Bowling 1997). A second wave of questionnaires was sent in March 2000 after issues relating to addresses of non-respondents had been checked (see Appendix Six – Covering Letter 2). The covering letter was changed to incorporate a section on being researched, also the colour of the questionnaire was changed from white to pink, which assisted in data categorisation and pastel colours were linked to increased response rates (Cormack 1994).

The response rate following second mailing was 72% (n=340) and although Bowling (1997) suggests that self-administered questionnaire should be restricted to closed-ended questions, my results found that informants were willing to add further comment. I linked this to relevance and structure (Polit and Hungler, 1997). Although long, the questionnaire was 2 pages, covering 4 sides of A4, reduction would have left the questionnaire too superficial. The overall response rate was pleasing, as it can be as low as 30% (Keats 2000) with Bourque and Fielder (1995) suggesting 20%. Information on the excel file was utilised to investigate issues of non-response as such informants may differ in some important way and was a potential source of sample bias (Bowling 1997). Bowling (1997) identifies that non-response can vary according to geographical area, social class, ethnicity and age. However, no significant detail of difference was found between those who responded and those who did not.

5.6.3 Data Analysis

SPSS Version (10.0) was used to create variables for the questionnaire data. Data input focused on cases as variables in row/rectangular format, with each answer or piece of information as a value (Miller et al 2002, Kent 2001). The program produced descriptive statistics i.e., percentages. I manually assessed the first 100 questionnaires to provide appropriate variables, but the variables did need continuous reformulating. This took more time than expected and, perhaps, reflected my performance as a first-time user of the program. Questions facilitating more in-depth responses were analysed using content analysis (see Section 5.8 for discussion). Comments relating to the membership of interview panels (Question Two) were not used in the analysis due to potential difficulties with memory bias.

There were a number of important issues that impacted on the direction and depth of the data analysis of the national survey. One of the main focuses of the analysis was

addressing key objectives of the research study (see Section 5.1). Quantitative analysis focused on the provision of a demographic profile of lay members and the identification of aspects of their role development within PCGs. Chapter Six reveals that the questionnaire fulfilled these key objectives, providing an overview in relation to age, ethnicity, gender, occupation and social class. Furthermore, quantitative data analysis identified 15 specific roles/responsibilities in relation to lay membership. Similarly the analysis was particularly facilitative in the identification of 12 subgroups associated with lay involvement as well as identifying potential candidate availability and selection for Phase Three and highlighting the importance of negative lay experiences. Although survey data provided the opportunity and capacity for a more detailed analysis, this was restricted by the small number of informants within areas of interest i.e., the age ranges 18 –30 (n=3); 71 + (n=11) and minority ethnic groups (n=14). Further exploration seemed of limited benefit, more important was identifying the issue of continuing under representation in terms of age and ethnicity and potential recruitment difficulties. Furthermore, non-parametric tests exploring potential differences in relation to gender/social class and role development proved inconclusive.

5.7 Telephone Interviews

Questionnaires and interviews can be seen as complementary within a multi-method study, often relating to different points of the research process (Arksey and Knight 1999, Oppenheim 1992). Following on from the national survey in 2000, telephone interviews commenced in March 2001 with informants identified from the questionnaire. Keats (2000:7) in discussing interview technique identifies that different contexts and purposes will require different approaches and this was particularly pertinent to Phase Three as three distinct groups of lay member were to be interviewed in regards to role experience. The strategy reflected quantitative and qualitative approaches and utilised structured, semi-structured and in-depth interviews. The three groups, subject to enquiry were: -

- Lay members who had become the lead/chair for public involvement within their primary care group
- Lay members who had expressed particular negative aspects to their role
- Lay members who had become non-executive directors or Chairs within primary care trusts (operational in April 2001)

All informants were initially contacted by telephone regarding further participation and an advanced letter was sent regarding purpose and confidentiality (Frey and Oishi 1995).

5.7.1 Lead/Chair for Public Involvement

The sampling method reflected a stratified random sample. The formation of strata related to age, locality, ethnicity, gender and geographical area with a random sample taken from these subgroups (Fink 1995, Cresswell 2003). The 20 informants covered 7 regions across the country; the South East region was excluded from Phase Three (see Chapter Six Summary for further discussion). Data analysis of the questionnaire had identified the view, by some informants, that they were being over-researched and part of the sampling criteria for Phase Three was to approach potential informants who were not involved in research relating to PCGs and/or public involvement.

Twenty lay members took part in a structured telephone interview with informants identified as the leads/chairs for public involvement within primary care groups via the national survey (n=162). Interviews with these informants incorporated an interview schedule, which focused on five specific areas (Box 30 & Appendix Seven - Interview Schedule). The structured telephone interviews were economic and aided a rapid pace of data analysis (Oppenheim 1992). The schedule was drawn from data analysed in Phases 1 & 2 and was piloted on five lay members, to aid content validity (Litwin 1995, Arksey and Knight 1999). Revisions to format were made and difficulties with the recording and telephone equipment were highlighted. An Internet search proved invaluable, providing a small portable instrument to aid in recording telephone conversations. I managed to develop this into a pocket size, portable tape recorder that I could plug into most phones. The revised schedule and new equipment was piloted on a further 5 lay members with no further difficulties identified.

Although it is suggested that detailed schedules are not particularly apt for telephone interviewing (Polit and Hungler, 1997), informants were notified by letter pre-interview regarding the specific content of the interview schedule and approximate time it would take to complete. Furthermore, the schedule provided a standardised route for data collection (Oppenheim 1992, Cresswell 2003) addressing issues of reliability (Frey and Oishi 1995). I ensured that each informant was given the same

questions and wording, in the same sequence with no deviation from the schedule itself (Oppenheim 1992, Arksey and Knight 1999). This entailed asking the same questions, ensuring the same meaning, same words, same sequence and setting. The interviews were recorded. Open questions within the interview schedule were transcribed and analysed utilising content analysis (see Section 5.8 for discussion), factual content was analysed utilising SPSS (Version 10.0) (See Chapter 8).

BOX 30
Interview Schedule

Role as lay member
- Length of service
- Training (actual and identified needs)
- Definition of role
- Developing relationship with Board members
- Overall experience

Lead/chair in public involvement
- Appointment to lead for public involvement
- Developing a public involvement strategy
- Subgroup/subcommittee membership
- Identification of methods utilised to involve the public
- Effectiveness and evaluation of methods
- Budget allocation
- Public Involvement Facilitators
- Successes and obstacles related to public involvement

PCT status
- Identification of date to go to Trust status
- Planned mergers
- Public consultation & lay member involvement
- Methods utilised for public consultation
- Views on non-executive directorship & appointment system & PCT governance

Previous experience
- Previous held positions
- Involvement in previous public involvement initiatives
- Knowledge of public involvement methods

Personal & Comments
- Disability
- Important areas not discussed
- Further comments

5.7.2 Negative Experiences

Seven lay members were interviewed regarding their negative experiences as a board member of a primary care group. 8.5% of informants had identified specific negative experiences on the questionnaire (see Section 6.4). These interviews reflected a particularly small sample size; many with negative experiences were not willing to be involved in Phase Three (see Question 19) reducing the sample pool. These were open-ended interviews of an exploratory nature (Oppenheim 1992). As such they covered specific issues (Britten 2000) highlighted within each lay members' questionnaire as the main areas for discussion. The interviews focused on exploring interviewee's perspectives and feelings (Oppenheim 1992. Arksey and Knight 1999) to gain a deeper understanding of the issues raised (Wengrat 2001). The interviews

were taped and transcribed and analysed using content analysis (see Section 5.8 for discussion).

5.7.3 Non-Executive Directors & Chairs

Thirteen non-executive directors and four chairs of PCT boards took part in a series of semi-structured interviews. The first and third interviews were utilised for data analysis within this research study and covered a time interval between April and October 2001 (see Appendix Eight – Covering Letter 3). The informants reflected a stratified sample, formation of strata related to age, gender and geographical area. They held positions in Primary Care Trust's across seven regional centres: - Eastern, West Midlands, Southeast, North and Yorkshire, Southwest, Trent, North and West, again London region was excluded for the reasons discussed earlier. Potential informants were again identified via national survey, aided particularly by information given in Question 8 (i.e., operating level/future changes).

The semi-structured interview technique reflected a loose structure consisting of open-ended questions related to general identified issues (Britten 2000). The questions were prepared in advanced (Wengrat 2001). Areas for discussion came from the analysis of interviews with lay members who were leads in public involvement in PCGs, informal discussions with non-executive directors of established PCTs, discussions with representatives of the National Association of Lay Members in Primary Care as well as a literature review focusing on public involvement within Primary Care Trusts, therefore, addressing issues of content validity (see Sections 8.3 & 8.4 for subject areas).

Informants were contacted in March 2001 by telephone and a covering letter was then sent (see Appendix Eight – Covering Letter 3). All first interviews were conducted in May 2001. The telephone interviews were recorded and transcribed, lasting approximately 15 to 20 minutes long. The length of the interview was established for two primary reasons, one the length of time required to transcribe 17 interviews (Silverman 2005) and informants resistance to longer interviews. To counteract the difficulties with these short interviews, informants were asked if they would have

further interviews 12 weeks after going to trust status (July 2001) and at six months (October 2001).

5.7.4 Data Analysis of Telephone Interviews

Interview transcripts were subject to content analysis, which involved the manual categorisation of data (see Section 5.8 for full discussion). Discrete data from interviews with non-executive directors relating to PCT governance was re-analysed using discourse analysis to explore issues of power and dominance (see Section 8.3.3.1). Discourse analysis is a method that has gained in popularity within nursing research (Mills 1997), with the focus on text itself (Cheek 2000) and acknowledges that information is humanly constructed (Keddy 1996). The concept can be left undefined (Mills 1997) although Taylor (2001:5) gives a general definition describing the concept as '... the close study of language in use'. A number of approaches are linked to discourse analysis: - conversational analysis (see Cheek 1997, Wooffitt 2001), sociolinguistics and corpus analysis (see Yates 2001), interpretative repertories (see Edley 2001), genealogical analysis (see Carabine 2001) and discursive models (see Heslop 1998, Horton-Salway 2001). This research incorporated the use of critical discourse analysis.

Lupton and McLean (1998) and Grbich (1999) discuss the method of critical discourse analysis with content analysis replaced with a more interpretative, investigative analysis. Lupton and McLean (1998) see such analysis as focusing on the use of language and discourse, placing the text in their socio-cultural and political contexts, revealing the broader context. The main focus is to identify power relations and structures (Lupton and McLean 1998, Wetherell et al 2001). The interest is in how language is important as part of wider social processes and activities and is known as extra discursive. This type of discourse analysis is strongly related to controversy, as it involves the study of power, domination and resistance, an important aspect of the research study (Fairclough 2001, Wetherell et al 2001). The analysis also takes a discursive approach, which is the identification of patterns and terms in the language within a particular topic or activity (Wetherell et al 2001). This was utilised specifically to explore non-executive directors discussion of the relationship between the Board and Executive Committee within a PCT.

Different approaches of discourse analysis have been utilised in a number of nursing settings: - nursing within accident and emergency (Heslop 1998), the effects of medical notes in constructing the patient (Cheek and Rudge 1994), discourse and women hospital managers (Hood et al 1998), professional and client interaction (Cheek 1997) and the construction of critical pathways (Gibson and Heartfield 1996). Fairclough's (2001) discussion is particularly pertinent to this research study with an emphasis on the negative effects of globalisation on democracy, a strand of which can be seen in the democratic deficit within the NHS at time of the research.

The ten stages of discourse analysis identified by Potter and Wetherell (1987) were utilised to analysis interview transcripts relating to PCT governance: -

1. Research Questions
2. Sample Selection
3. Collection of Records and Documents
4. Interviews
5. Transcription
6. Coding
7. Analysis
8. Validation
9. Report
10. Application

The discourse analysis also involved the manual categorisation of data and is discussed in Section 5.8.

5.8 Manual Categorisation of Interview Transcripts & Questionnaire Comments

Interview transcripts from Phases 1 & 3 of the research and comments relating to Question 20 of the national survey (see Appendix Three) were subjected to content analysis and coding. Coding into categories has been described as an essentially comparative process, by which various accounts are compared with each other to classify recurring themes or common themes in the data set (Wetherell et al 2001, Green and Thorogood 2004). A straightforward and conventional way to conduct this type of analysis is to use a 'scissor and paste' approach (Green and Thorogood 2004:177, Miles and Huberman 1994) and this was employed in this research project.

Firstly, transcripts of interviews from Phases 1 & 3 and comments from the questionnaire were photocopied and the originals returned to storage (see Riley 1996). The photocopied data sets were subjected to a process similar to that identified by Krueger and Casey (2000: 132-5) cited in Green and Thorogood (2004:179): -

- Use of a long table (or walls, or floor) covered with flip chart or newspaper, with sections headed with themes (or interview questions)
- Distinguish each of one set of transcript copies by printing each on different coloured paper, or using coloured lines down margins so that the original source of extracts cut out can be identified
- Cut the transcripts up into separate extracts
- Begin sorting extracts by assigning them to sections, and then comparing each new extract with the growing pile: is it similar, or should you start a new pile or section?

Within this study observations were made by the systematic reading and re-reading of the photocopied texts to develop coding schemes (Green and Thorogood 2004). The codes assign units of meaning to the transcribed descriptive information and are generally attached to 'chunks' of information of varying size e.g., words, phrases, sentences or whole paragraphs (Miles and Huberman 1994:56). In some cases such as Phase One such schemes developed from interaction with the empirical data (Green and Thorogood 2004:178), in other cases (see Phase Three – interviews with non-executive directors) coding schemes were developed around interview questions. In all coding, coloured highlighter pens were utilised to identify potential categories (see Crabtree and Miller 1999) and were made visible in the margins of the texts (see Green and Thorogood 2004). The transcripts were then cut up and a long table was used to build up piles of colour-coded categories. Although described as a 'low technology' approach, Green and Thorogood (2004:179) highlight the effectiveness of this method as it allows the researcher to compare, contrast and build up categories and to develop meaning from the data.

As a researcher, I was aware that there were different types of computer-assisted qualitative data analysis software (CAQDAS) available to assist in such content analysis (see Miles and Huberman 1994, Spencer et al 2003). However, the use of such software can result not in more sophisticated analysis but instead the potential displacement of the researcher from the analytical process (Bowling 1997, Spencer et

al 2003). Crabtree and Miller (1999:169) suggest that scissor and paste represents a simple but elegant approach. An important advantage for me was the creation of a physical tangible environment in which I could visually observe categories emerging, which aided in the process of connecting and displaying the data (see Crabtree and Miller 1999) with a feeling of being central within the overall process.

Wetherell et al (2001:39) suggest that the key difference between discourse analysis and other types of data analysis is not the initial process. This can be seen to good effect in Potter and Wetherell's (1987) stages of discourse analysis (see Section 5.7.4), the stages replicating much of the discussion on content analysis at the beginning of this section. The difference focuses on the analytic concepts involved within the discourse analysis and these develop from the theoretical stance of the research (Wetherell to 2001:39). Therefore, the concepts of power, domination and resistance as well as patterns of language influenced the development of the coding scheme within this specific piece of data analysis.

Crabtree and Miller (1999:169-171) also identify the importance of corroborating and legitimatising the results from such data analysis and advocate the use of an auditor to address issues relating to the potential fabrication, discounting and misinterpretation of evidence. Green and Thorogood (2004:177) also suggest that lone researchers can find it productive to consult with colleagues or supervisors during the early stages of data analysis. Wilmot and Ratcliffe (2002) elaborate on this in their research on the principles of distributive justice. Transcripts from group discussions with members of the public were also independently analysed by a third colleague to validate their own analysis. Similarly, Kerr et al (2006) ensured that their content analysis (relating to smoking cessation) was subject to peer review. Similarly transcripts within this research study were sent to internal and external research supervisors for independent categorisation.

5.9 Conceptual Framework

As discussed in Chapter 2, emerging themes of power and domination became more prominent and integral to the research as the study proceeded. Reed and Procter (1995) highlight the importance of recognising and discussing the political context, with researchers sensitising themselves to the politics of the organisation studied. It

became clear that methodology established at the beginning of the research could not adequately address such emerging issues. Brown (1999) also criticises research focusing on involvement for its narrow use of methodology, the lack of socio-political context in many research studies, perhaps, suggests too strong an emphasis on an individualist perspective (Thompson 1995). Brown (1999) warns that solely descriptive studies fail to explore critical issues and such a viewpoint was to impact on my theoretical stance and my own use of description.

Like Reed and Procter (1995), Brown's (1999) discussions identify the importance of the organisational context in studying public involvement initiatives and he suggests that the culture, attitudes and power within the organisation are key variables. As these are difficult to measure he urges that research approaches draw more widely from social and political theory (Brown 1999:175/176). In addressing the issue of the lack of theoretical depth in previous public involvement research (Brown 1999), I decided to utilise a conceptual framework to address issues of power and domination within my own study. Part of this strategy incorporated the use of a Foucauldian approach, which was utilised to re-analysis discrete data taken from Phases 1, 2 & 3 and the results of the analysis are presented in Chapter Nine.

The work of Michel Foucault has been highly influential within health related research and health policy (see Nettleton 2006). Watson (2000:75) suggests that Foucault has shifted the analysis from grand theory to specific analysis of specific policies at a specific time, which provides original insights. Examples of Foucauldian interpretations of health policy can be seen in the work of Hughes and Griffiths (1999) in their examination of NHS contracting and commissioning, Light's (2001) review of economic policy and managed competition, Joyce's (2001) analysis of NHS priority setting and rationing, Lynch's (2004) interpretation of NHS national targets and Sheaff et al (2004) explanation of recent changes in general practice. This focus on specific policies at a specific time (Watson 2000) was particularly advantageous to this study, which addressed the implementation of a specific health policy – public involvement – in a specific timeframe (1999-2001). Further discussion on the advantages and choice of a Foucauldian approach can be found in Section 9.1.

However, Foucault has been criticised in a number of areas. Clegg (1989) identified that Foucault had no training within the discipline of sociology; hence his work lacks any sociological framework. Fox and Miller (1995) identify that some sociologists have argued that his work is ambiguous and contradictory. For example, although sociologists share the view that medical knowledge is social constructed, some disagree with Foucault's view that bodies are simple discursive constructions (Nettleton and Gustafsson, 2002:3). Clegg (1989) also suggests that Foucault understated the importance of Weber's contribution to arguments regarding discipline (see Chapter Four) in his discussion of disciplinary power. Similarly, there is disagreement with Foucault's discussion on normalizing judgment (see Section 9.2), particularly the assumptions made regarding health professionals (White 2002). However, White (2002) counter argues that many health workers do have experience of the labeling associated with the concept and may have, from time to time, engaged in labeling in their professional capacity.

Although, Fox and Miller (1995) suggest that sociology addresses much broader issues that those covered by Foucault's work, they do acknowledge Foucault's influence on post-structuralist movements, particularly those associated with philosophy, literary theory and emancipatory politics (Fox and Miller 1995:121). Furthermore, Fox and Miller (1995:120) identify positive aspects of Foucault's work, highlighting the originality of his accounts, a point echoed by Nettleton (2006), the authors go on to suggest that the ambiguous and contradictory elements could be acceptable bedfellows within a post modernist approach to sociology. White (2002:27) also points to comparative higher level of analysis and empirical abstraction associated with Foucault's work, indeed, the level and depth of his analysis in relation to disciplinary power proved a strong motivation in utilising his work within this research study.

Watson (2000) also suggests that Foucault paid little attention to gendered dimensions in relation to power (Watson 2000). However, White (2002) identifies a number of Foucauldian-Feminist positions. White (2002:143) goes on to highlight that feminism and Foucault due share specific principles and ideas, both focus on the centrality of the body in social relationships. Foucault's view that power was diffuse and integral to all social relationships enabled feminists to give an account of how women can

incorporate, as well as resist, patriarchal images of their bodies (White 2002:143). However, although acknowledging potential gender issues within this research, this was not the main focus of the study. Westwood (2002) also identifies criticism relating to the lack of collective struggle within Foucault's analysis, again, in relation to this research study, discussion of collective struggle against medical dominance and central policy directive seemed unrealistic, more, interesting was the notion of resistance within each social interaction (Foucault 1978). Also absent in Foucault's work is the discussion of the state, described as 'an analytical chasm' (Westwood 2002:18), however, Foucault addresses this criticism: -

'I don't want to say that the State isn't important; what I would say is that power relations and hence the analysis that must be made of them, necessarily extend beyond the limits of the State' (Foucault 1977a:142).

Allen (2003) also criticises the fact that not enough attention has been paid to forms of power (Wrong 1979), this included domination, authority, manipulation, inducement and seduction. However, White (2002) does highlight aspects of coercive power within Foucault's work as does the discussion on disciplinary power in Section 9.2, which clearly identifies issues relating to coercion and manipulation. The view of power as everywhere is also problematic for Allen (2003), as this minimises the experience of what it means to have had a brush with power. However, this is probably addressed by Foucault's suggestion that individuals do have choice and agency with the ability to act on their own worlds and affect their own biographies (Westwood 2002).

5.10 Ethics

Polgar and Thomas (2000:27) suggest: -

'A research process is judged to be ethical by the extent to which it conforms to or complies with the set of standards or conventions in the context in which the research is to be carried out and community standards'.

The context of the research study is established earlier in the chapter, focusing on an investigation of the interpretation and implementation of health policy, involving professionals, managers and members of the public. Green and Thorogood (2004:56)

also suggest '...what constitutes 'ethical practice' is different in different places and time, and across different disciplines'. The authors link their ethical discussion to four distinct areas – formal ethical review (via ethics committee), legal frameworks, disciplinary codes of practices and ethical conduct. At the time of the commencement of the research study in 1999, the research proposal was checked with an ethics committee. As the research did not involve patients or patient care, ethical clearance was not seen as a requirement. Therefore, the onus was on myself, as the researcher, to develop an ethical stance. For example, two informants from PPGs were interviewed, however, this was in their capacity as leaders of these groups and there was no discussion of patient experience or treatment. Any discussion of specific patients or treatments within the fieldwork was not recorded; such material was seen as not relevant to this study.

However, Barrett and Coleman (2005) identify that ethic committees have changed since 2001, with a move to a system of research governance. Such committees were now answerable to Strategic Health Authority in England and to the Central Office of Research Ethics Committee (Barrett and Coleman 2005). The governance was identified by Department of Health (2001d) in 'The Research Governance Framework for Health and Social Care' and updated again in 2005. The World Medical Association also published guidelines in 2002 on the ethical use of health databases (Barrett and Coleman 2005). As a researcher now, as Barrett and Coleman (2005) discuss, I would need approval from the research and development department of the particular PCT for a research study that involved NHS staff or patients. As Green and Thorogood (2004) suggest, social research has been less regulated and at this period of time ethical approval was generally left to individual institutions and this was the case with the research study. However, during the history of the study I transferred registration to the University of Hertfordshire. The Research Degrees Board assessed the study, again, the board findings were that at that stage of the research it was not necessary for the research to be considered by the University of Hertfordshire Ethics Committee.

Silverman (2005) links ethics to the researcher's responsibilities to those studied, most discussions focus on informed consent, confidentiality and anonymity.

Informed consent involves ensuring that the purpose of the research is clearly explained (Bourque and Fielder 1995, Lewis 2003, Silverman 2005). Case studies received an introductory letter and copy of the research proposal and objectives. Copies were also given to group members and I was always introduced as an independent researcher. Participants in the national survey and telephone interviews also received covering letters discussing the nature of the research and issues of confidentiality (Fowler 1993). Specific voiced concerns were addressed e.g., I was asked not to attend the meeting of a newly formed Patient Participation Group furthermore copies of data analysis were sent to informants in Phase 1 & 3 (Stake 1998).

However both PCGs had moved to PCT status during data analysis and tracking informants did prove difficult. Polit and Hungler (1997) highlight that written informed consent is hardly ever obtained. When data collection is via a self-administrated questionnaire the general assumption is of implied consent – a returned completed questionnaire reflects voluntary consent. Such consent also includes issues relating the length of the study, funding, how the data will be used and what is required from the informants (Lewis 2003, Green and Thorogood 2004, Silverman 2005). In all cases participation should be voluntary (see Declaration of Helsinki revised 2000 cited in Green and Thorogood 2004). However, as Green and Thorogood (2004) suggest most health care settings involve changing personnel, therefore, it is difficult to ensure that all participants present at every point of the study are fully informed and this is particularly true with my observations of large process events. Silverman (2000:202) makes some interesting comments on audio-taping, suggesting that the researcher should obtain consent for a number of areas such as publications, presentations, use of data by other researchers. This was certainly not fully addressed, also consent in relation to archives needed further attention (Lewis 2003).

Another important ethical issue is that the informant should not be harmed through such participation, particularly they should not suffer undesirable consequences as a result of the study (Bourque and Fielder 1995, Taylor 2001, Wengrat 2001) and this issue was addressed with the use of anonymity and confidentiality. Stake (1998) suggests that case studies often focus on matters of public interest; however, there remains the chance of exposure or embarrassment. Both case studies remained

anonymous within the research report and there were no concealed observations (Grbich 1999). Transcripts from case studies and telephone interviews were also anonymous (Arksey and Knight 1999), personal information, where possible, was replaced with an identifier (Taylor 2001, Lewis 2003). Where information could not be de-personalised, an emphasis was placed on the secure storage of data (Fowler 1993, Bourque and Fielder 1995) also highlighted by the Helsinki Declaration and Data Protection Act 1998 (Green and Thorogood 2004, Barrett and Coleman 2005).

5.11 Strengths & Weaknesses of the Research Study

Many of the difficulties encountered within the research study related to time management and the inexperience of being a first-time researcher, particularly in the planning and implementation of research methods. The rapid development of PCGs reflected a paralleled rapid response in accessing case study sites (within six months). This perhaps explains the slow development of effective techniques for field notes and the organisation of data, which at times felt overwhelming. However, the use of Yin's case study design provided an essential support in developing effective strategies for data collection and developing adequate boundaries for the study. There were some communication difficulties with Case Study B, leading to a stronger reliance on secondary data than Case Study A. Although my initial interview technique could have been described as a little rigid, this developed over time, growing confidence was aided by highly portable recording equipment.
Further time management problems were experienced as the original research proposal was extended (see Appendix Nine – original proposal). However, I still underestimated the time required for data processing and its interpretation in all phases of the research – a useful lesson for future projects.

On reflection a more disciplined approach would have reduced the pressurised nature of analysis. The design and response rate for the national survey proved a particular highpoint of the research. However, the exclusion of the issue of disability and therefore aspects of equal opportunities, despite piloting, from the questionnaire remains a great disappointment. Although now addressed by agencies such as the Appointments Commission. The reluctance of lay members to discuss their negatives experiences of involvement reflected in a small sample size in Phase Three (n=7), perhaps an area that could be developed in the future. However, their experiences do

incorporate important lessons in relation to adequate support. The explanatory phase became crucial in trying to come to terms with the relative slow progress of involvement within the two-year study period and provided a first encounter with the work of Michel Foucault.

CHAPTER SIX

Survey findings

Introduction

The questionnaire was developed to address research objectives regarding the provision of a demographic profile of lay members serving on the governing boards and the exploration of lay role development (see Section 5.1). Areas addressed on the questionnaire focused on selection process, training, role development and a profile, which included age gender, ethnic origin and occupation (see Appendix Three– Example of Questionnaire). The findings are presented using the three identifiable sections within the questionnaire: - personal and occupational profile and the role of the lay member. In addition a further section 6.4 is presented, which relates to lay members' statements made on role allocation (Question 7) and further comments (Question 20). The questionnaire was sent out to 481 lay members across England, 12 lay members had resigned their positions at the time of the survey giving a potential response of 469. The final return was 340 questionnaires giving a response rate of 72%. The data from the questionnaire was entered into SPSS (10.0) and analysed using descriptive statistics. Informants comments made in relation to Question 7 and Question 20 were analysed utilising content analysis and manual categorisation.

6.1 Personal Profile

Within this section of the questionnaire informants were asked to give information regarding their age, gender and ethnic origin.

6.1.1 Age Range of Lay Members

As can be seen from Table 1, the largest group of informants were aged between 51 to 60 years old (34.5 %, n=117). An under-represented group were informants that were between the ages of 18 to 30 years old (n=3), a finding also supported in research by Davies (2001) and James and Willitts (2000). The data supports observations that participants continue to be middle-aged (Giddens 1998, Persaud 1999). Continued under-representation suggests that young people lack power both as citizens and users (Barnes and Warren 1999) and Curtis et al (2004) suggest the need to develop a variety of ways of eliciting views from this group.

Table 1

Age of Informants

	n	%
18 to 30	3	(0.9)
31to 40	32	(9.5)
41 to 50	81	(23.9)
51 to 60	117	(34.5)
61 to 70	95	(28.0)
71 and over	11	(3.2)
Base	*339	(100)

*1 missing observation

6.1.2 Gender

The number of female lay members slightly out numbered males, with female informants being 50.4% and males at 49.6%. This seemed more evenly distributed than Davies's (2001) research on regulatory boards, which produced a 40:60 ratio. The level of female lay involvement may have been due to the numbers of women actively involved in the voluntary sector, particularly the CHC (43% of CHC members were women in 1976 - Klein and Lewis (1976)). Policy may have indirectly assisted this gender balance as CHC members had been allowed to apply for lay member positions (HSC 1998/139). At first glance this gender balance has been transferred to PCTs, 48.7% of non-executive directors are female (Appointments Commission Survey, 2005), a previously male dominated area (Hogg 1999). However, the same survey reveals that three quarters of the PCT chairs were male. This position was highly prized and seen as the most influential position in Phase Three of the research.

6.1.3 Ethnic Background

The majority of lay members classified themselves as white. In taking all white groupings (White – British, White – European, White English, White Other) into account, 95.8% (n=325) were from this ethnic group. Only 4.1% (n=14) of lay members were from minority ethnic groups, the largest minority ethnic groups were Black British (0.9%, n=3) and Indian (0.9%, n=3), with the national average in England and Wales standing at 5.9% (James and Willitts 2000). As with younger

people, minority ethnic groups remained under-represented and the opportunity to have a more inclusive membership seems to have been lost in the case of PCGs.

Table 2

Ethnic Group

	n	%
Black – British	3	(0.9)
Black Caribbean	1	(0.3)
Indian	3	(0.9)
Pakistani	1	(0.3)
Asian	1	(0.3)
White – British	314	(93)
White - European	2	(0.6)
White other	7	(2.1)
White English	2	(0.6)
Other ethnic	5	(0.6)
Base	*339	(100)

*1 Missing Observation

6.2 Occupational Profile

A number of areas were addressed within this final section of the questionnaire. This included paid occupation, previous occupation if retired, type of employing organisation, social classification and previous NHS employment.

6.2.1 Paid Occupation

The majority of lay members had a paid occupation outside of the PCG, 54.1% (n=184), of those 55.1% were in full-time and 44.9% were part-time employment. The six most prevalent jobs for paid occupation were consultant, manager, academic, director, teacher and development worker. Many of the consultants identified themselves as self-employed, James and Willitts (2000) research was able to quantify this area, identifying that 27.6% of their sample came from this group, for a full list of occupations (see Appendix Ten).

6.2.2 Organisational Categorisation

The six most prevalent organisations identified within the occupational profile were consultancy, private sector, education, voluntary organisation, charity and local authority.

Table 3

Type of Organisation

	n	%
Voluntary organisation	24	(13)
Charity	18	(9.8)
Local government	12	(6.5)
Other public sector	15	(8.2)
Private sector	27	(14.7)
Social services	2	(1.1)
Education sector	25	(13.6)
Local authority	16	(8.7)
Consultancy	42	(22.8)
Church of England	3	(1.6)
Base	*184	(100)

*156 Missing Observations

6.2.3 Occupations Pre-retirement

Previous occupations of lay members who had retired were similar to that of lay members in paid employment. Prevalent occupations within this group were manager, teacher, director, consultant and civil servant, for a full list of retired occupations (see Appendix Ten). 34.7% of the informants had held senior positions within their organisations. Senior positions were defined as head teacher or head of a department, directorship/chief executive of a company, chief executive of a company. The prominence of high achievers in public involvement was also identified in Davies' (2001) research. 40 informants identified that they had an additional unpaid occupation such as voluntary work, councillorship and carer. These findings tend to agree with comments made by James and Willitts (2000), which linked flexible employment patterns to the ability to attend board meetings and committees.

Occupational (paid & pre-retirement) profiling again identified a number of parallels with earlier studies such as Klein and Lewis (1976). Education, local government, local authority and voluntary/charity organisations continue to be well represented. An interesting development is the notion of consultancy, with many of the consultants identified themselves as self-employed. Incorporating this information with the average age of lay members being 51 – 60 may suggest that such lay members could have taken early retirement and then developed their consultancies. An example of such consultancy was seen in Case Study A, an outside consultant was a member of the Community Participation Group (see Section 7.13), with a previous employment history at health authority level and was active in developing two public consultation initiatives.

6.2.4 Social Classification

The National Statistics Socio-Economic Classification (NS-SEC) was utilised to calculate the occupational profile into a social classification. As can be seen from Table 4, the majority of lay members were classified as Social Class 1. Social Class 1 is divided into two specific groups, 1.1 which relates to employers and managers of large organisations and 1.2 relating to higher professionals such as doctors and lawyers. Amalgamating both categories identifies that 46.9% (n=154) of lay members are from Social Class 1. Small employers and own account workers, make up 17.3% (n=57) of lay members.

Table 4

Social Class based on Occupation

	n	%
Employers and managers/large organisations	86	(26.2)
Higher professionals	68	(20.7)
Lower managerial & professional occupations	99	(30.2)
Intermediate occupations	10	(3.0)
Small employers & own account workers	57	(17.4)
Lower supervisory, craft and related occupations	5	(1.5)
Routine occupations	1	(0.3)
Long term unemployed & never had paid work	2	(0.6)
Base	*328	(100)

*12 Missing Observations

A recent survey of non-executive directors and chairs by the Appointments Commission (2005) show that there has been movement relating to minority ethnic groups, with 12.3% of appointments coming from this group. The same survey was able to give statistics on disability and 7.7.1% of appointees declared that they were disabled. However, the average of appointees continues to parallel this research remaining at 56+, there was no assessment of class status - an important omission (Appointments Commission Survey 2005).

6.2.5 Previous NHS Occupation

Almost a quarter of lay members had worked for the National Health Service (24.5%). Davies (2001:iii) describes this phenomena as the NHS mafia and results by Klein and Lewis (1976:79) also emphasis this longstanding relationship. The focus on lay involvement as the non-medical and non-professional element of service provision and decision-making is, to some extent, undermined by these results.

6.3 The Role of the Lay Member

This section of the questionnaire followed a chronological order, exploring the awareness of the position of lay member and the selection process, through to training, role development and group membership. It also included questions relating to the operating level of the PCG and its locality.

6.3.1 Awareness of the Position of Lay Member

Responses highlighted a variety of routes for gaining access to information regarding the position of lay member, 47.2% (n=160) of lay members had become aware of this position through the local press. However 40% of informants gained this awareness via an established relationship with the health service, voluntary organisation or local authority/government. These results support observations made by Davies (2001:ii) and her research into lay representation on regulatory boards. Although acknowledging the use of open advertisement of vacancies, she described word of mouth encouragement and informal efforts to create a field of candidates – this system operated alongside formal recruitment. Furthermore, Smith et al (2000) research into PCG recruitment within 59 PCGs identified concerns in reaching an adequate cross section of the local population and James and Willitts (2000) also identified the lack of access to unsuccessful applicants, which left questions whether

the selection process was biased. However, more proactive approaches to selection were identified by Smith et al (2000) and Case Study A, where public sessions were also held to discuss the position of lay member within the primary care organisation (see Section 7.4).

Table 5

Awareness of the Availability of the Post of Lay Member

	n	%
Local press	160	(47.1)
Told of vacancy	60	(17.6)
National press	7	(2.1)
General enquiry	6	(1.8)
Through CHC	27	(8.0)
Via Health Authority	19	(5.6)
Through voluntary organisation	13	(3.8)
Informed by health professional	3	(0.9)
Via patient participation group	3	(0.9)
Other route	7	(2.1)
Mixture of routes	18	(5.3)
Via NHS database	2	(0.6)
Via Local Authority	3	(0.9)
Via Council	6	(1.8)
Via meetings regarding PCGs	2	(0.6)
Via other NHS affiliation	3	(0.9)
Base	*339	(100)

*1 missing observation

6.3.2 Interview Attendance

The majority of lay members were interviewed for their position (97.9%). Those informants who were not interviewed had already been through a selection procedure for non-executive director positions. Under this system, successful interviewees would be entered onto a national NHS database and asked to fill positions as they became available. Comments regarding the interview, highlighted members of the

interview panel as well as the mode of interview (e.g. many noted the interview as thorough). However, this data was not statistically analysed due to potential memory bias as many of the lay members had been interviewed in 1998.

6.3.3 Public Involvement in the Selection Process

In response to the question on members of the public being involved in the interview process, 38.2 % (n=130) answered yes. However, 50% (n=170) of informants made additional comments on this question. The Community Health Council (CHC) and voluntary organisations were mostly likely to be defined as 'public'; although, interestingly many lay members also defined these organisations as non-public. Such observations perhaps suggest the continuing ambiguity of the concept of the 'public' and the need for organisational clarity in its operationalisation.

Table 6

Members of the Public involved in Selection

	n	%
Yes	130	(38.2)
No	200	(58.8)
Unsure	10	(2.9)
Base	340	(100)

6.3.4 Areas of Role Development

A majority of informants (99.6%, n=319) had identified that they had developed specific roles as lay member. Indeed, data analysis reflected a diverse and multiple role development. Many had taken lead positions within the organisational structure of the PCG, with 50.6% (n=162) becoming lead/chair for public involvement, comparable results were found by James and Willitts (2000). Others took on the role of vice Chair or Chair of the PCG; there were many examples of leadership or membership of a number of subgroups. Some lay members had incorporated a strategic role, developing public involvement or communication strategies. Other areas included developing specific projects such as walk-in clinics or patient participation groups. The development of a corporate identity was also highlighted with lay members describing themselves as representing the PCG; others highlighted

their accountability to the local community by identifying their role as public representative.

Table 7

Identified Roles and Responsibilities

	n	%
Group membership	319	(99.6)
Involved in public involvement	293	(91.5)
Lead in public involvement	162	(50.6)
Liaison	95	(29.6)
Representative of PCG	83	(25.9)
Other	72	(22.5)
Lead (other)	67	(20.9)
Public Representative	50	(15.6)
Strategic development	44	(13.7)
Specific Project work	26	(8.1)
Advisor/support	26	(8.1)
Information gathering	21	(6.5)
Group development	20	(6.2)
Vice Chair of PCG	16	(5)
Chair of PCG	7	(2.1)
Base	*320	(100)

*20 missing observations

6.3.5 Subgroup Membership

A majority of lay members were involved in subgroups within the PCG organisational structure (98.4%, n=319). 36.8% of lay members also had membership of external groups such as health panels, community health councils and local forums. The Democratic Health Network (2000) also identified lay members experiences of other health bodies, interestingly Davies (2001:I) describes this as the 'public duties circuit' with members holding multiple appointments. Although providing invaluable experience, there remain concerns that this situation further reduces the potential diversity of involvement. Only 8% of lay members stated that they were participants in lay member support groups, this is perhaps a little disappointing as Brotchie and

Wann (1993) and Bradburn et al (1999) emphasise the importance of networks and contacts to break the isolation associated with lay membership. However, within the life of the research a National Association of Lay Members was established. Membership of the subgroups could also be defined as a responsibility of the lay member and was incorporated to the roles and responsibilities.

Table 8

Subgroups	n	%
Public Involvement	204	(63)
HimP	102	(31.5)
Clinical governance	93	(28.7)
Mental health	70	(21.6)
Other subgroups	59	(18.2)
Specific primary care	39	(12)
Commissioning	34	(10.5)
Primary care development	31	(9.6)
Finance	24	(7.4)
Prescribing	19	(5.9)
PCT steering	17	(5.2)
Information Technology	10	(3.1)
Education/training	7	(2.2)
Human resources	5	(1.5)
Base	*324	(100)

*16 missing observations

The predominant subgroup membership was public involvement (also identified by Anderson and Florin and Alborz et al 2002) as well as strong representation from lay members in health related areas and clinical governance. Rowe and Bond (2003) assert that this almost automatic delegation to public involvement could have been linked to lack of role clarity and professional pre-conceptions. A much lower percent were involved in corporate issues such as commissioning, finance, information technology, prescribing and training (also a finding for Smith and Wilkin 1999). The range of subgroup membership varied from 1 to 9, with an average of 3 subgroups per lay member (also identified by James and Willitts 2000). The identification of

multiple roles and responsibilities as well as group membership reflected a substantial workload for many lay members.

6.3.6 Training Issues

The majority of lay members identified they had had training for their role (75%, n=247).

Table 9

Training

	n	%
Yes	247	(75)
No	82	(25)
Base	*329	(100)

*11 missing observations

66.8% (n=220) of informants made further comments on their training, areas highlighted were: -

- Quality of training
- Training organisations
- Subject of training
- Mode of training

83 informants identified quality issues and only 16 informants described the training as very good or excellent. Training difficulties related to: -

- Cost (e.g. expense of courses or travelling costs)
- Limited (e.g. inadequate content, infrequency of sessions)
- Wrong level (e.g. existing knowledge not taken into account)
- Not specific to needs (e.g. material too generalised)
- Poorly organised (e.g. trainers unsure of learning needs)

Such findings stand in contradiction to the Democratic Health Network (2000) research (focusing on councillor lay members of PCGs) particularly in relation to quality.

Training organisations were identified as: -

- Health authority
- Community health council
- College of health

- Other organisations (e.g., NHS Confederation, The Kings Fund)

The subjects of training sessions were identified as: -

- Board membership training
- Media and presentation skills
- Finance
- Health related subjects
- Information technology
- Clinical governance
- Chairing
- Primary care development

A number of reports and research such as Brotchie and Wann (1993) and Bradburn et al (1999) identified key areas of training. The research findings suggest that there is some evidence that contextual information and personal development issues were addressed, particularly presentational and committee skills. However, important areas are absent from this list such as inter-agency working, community development, NHS infrastructure and networking, such findings were further supported by data from both case studies and Phase Three interviews (see Section 7.5, 7.12 & 8.1.1).

81 informants identified the mode of training: -

- Training days
- Conference
- Seminar/workshop
- Away-days

6.3.7 Role Allocation

Although informants were only given the categories 'allocated' or 'volunteered' within the questionnaire relating to role allocation, 43.1% ticked both boxes (see Appendix Three – example of questionnaire). Comments from this question were analysed using content analysis and manual categorisation (see Section 6.4.1)

Table 10

Role Allocation

	n	%
Allocated	48	(14.6)
Volunteered	138	(42.2)
Both	141	(43.1)
Base	*327	

*13 missing observations

6.3.8 Operating Level & Locality

The questionnaire also asked for information regarding the operating level of the PCG (e.g., level one, two or three) and also whether there would be any changes in the level of the PCG following April 2000. Informants were also asked to identify the type of locality that most accurately described the operating area e.g., city, sub-urban, semi-rural and rural. These questions were administrative in nature and were utilised to identify a stratified sample of lay members for Phase Three of the research project (see Section 5.7.1).

6.3.9 Regional Response Rate

Part of the data analysis included categorising the response rate within the 8 regional centres for England operational at the time of the research. As can be seen from Table 11, the response rate was evenly distributed across regions, with lowest response rate in Trent and Eastern Region (9.7%, n=33) and the highest in South East (19.4%, n=66).

Table 11

Regional Areas of Primary Care Group

	n	%
Trent	33	(9.9)
London	43	(12.9)
West Midlands	39	(11.7)
North West	40	(11.9)
North and Yorkshire	42	(12.6)
South East	66	(19.7)
South and West	38	(11.4)
Eastern	33	(9.9)
Base	*334	

*6 Missing Observations

6.4 Content Analysis

Comments made by informants related to Question 7 (role allocation) and Question 20 (further comments) were analysed utilising content analysis and were manually categorised.

6.4.1 The Allocation of Roles

In analysing data regarding role allocation four categories emerged: - negotiation, expectation, uncertainty and exclusion, assertiveness.

Negotiation

Some informants identified that they had freedom of choice relating to role allocation, which suggests the ability for some lay members to build on existing skills and experience (Brotchie and Wann 1993).

> LM130: Created some roles with CEO and Chairman discussion
>
> LM184: I both volunteered and in some cases asked to represent board in the light of my knowledge and interests.
>
> LM154: ...in the early days the different roles seemed to fall naturally to those with specific skills and abilities.

Expectation

31 informants identified that there was a role expectation related to role allocation. Such expectation focused on public involvement, interestingly none of the training sessions (see Section 6.3.6) identified focused on this area.

> LM126: In the setting up process it seems natural that the lay member speaks for the public.
>
> LM481: It was half expected being the lay member that I would take on PI

Uncertainty and Exclusion

Some informants identified that the board was not sure about the role of the lay member and therefore which roles would be appropriate, further discussion of such difficulties was developed in Chapter Eight (see Section 8.2.2).

> LM535: The PCG didn't/doesn't really know what to do with me. It doesn't want to give me a role but feels it has to.
>
> LM494: Little real understanding of the role by practitioners

Others received unwanted roles or were refused roles.

> LM492: For the Partnership Board, no GP could be found to go on it. The CE wanted a GP, I said we must be represented and finally volunteered. A GP said I shouldn't do it as it should be a GP but no GP would still volunteer, no payment for attending.
>
> LM485: Been excluded from clinical governance and prescribing.

Assertiveness

The need to be assertive when volunteering for or accepting roles was also identified and it is seen as an essential aspect of personal development for lay representatives (Brotchie and Wann 1993, Bradburn et al 1999).

> LM140: If I had not offered myself on any of the subgroups I would be left out. I waited for any offers but was not asked at all; while other GPs, nurses, social services were asked.
>
> LM262: I think it depends on the kind of person you are. If you are not confident to participate fully it would be easy to be overlooked.
>
> LM156: Some roles were automatically allocated e.g., public involvement. Others I had to fight for e.g., membership of clinical governance.

6.4.2 Further Comments

Six categories emerged through the analysis, positive experiences, research, identified difficulties, previous experience and negative experiences.

Positive Experiences

Many of the informants identified that they were having a positive experience as lay members. The role was described as interesting and rewarding, a view supported by case studies and Phase Three data analysis (see Section 8.1.3).

> LM332: This has been the most fascinating job I have ever done. There was a steep learning (NHS jargon is impenetrable) but immensely rewarding.

Positive relationships with other board members were also described, the fact that they were accepted as colleagues and emphasising teamwork and trust.

> LM134: Found the position very rewarding, well accepted by other board members, previous experience as CHC member and Chairman very helpful.

Others highlighted that they were motivated and keen to become involved.

> LM126: I was keen to get involved as I had been and remain in a patient group and it seemed a brilliant way forward that as a patient you could be considered part of health planning and its future.

Research

Informants highlighted a number of issues related to research; some of these comments were general relating to being researched, other comments focused specifically on this research project. It became clear from the comments that lay members were being asked for information from a number of sources and some queried the value of such research

> LM331: I speculate what value this survey will offer and hope that you will be able to publish findings accessible to lay members and others…

Others were not aware that their details would be available on national databases.

> LM273: I didn't realise how many address databases I would be on …'

Accessibility to the results and findings of this research study was also highlighted as well as areas of weakness within the questionnaire design such as the lack of questions relating to disability (three informants identified themselves as having disabilities), whilst others criticised the lack of questions on voluntary work.

> LM384: I know it is difficult to set up questionnaires but as a disabled person I promote disability, equality on behalf of many others. Whilst there is a section for gender/nationality why has disability not been included …'

Identified Difficulties

This category focused on three specific areas, organisational difficulties, role difficulties and difficulties with the PCG board. Some of the lay members saw the new organisational structure negatively, with concerns focused on the level of bureaucracy.

> LM297: I have serious reservations as to the effectiveness of PCGs and public involvement.

Others areas identified were the speed of organisational change and the lack of public awareness of new organisational structures.

> LM225: The workload is immense, the speed is remarkable, teamwork and trust are excellent inside the board, not convinced the public are aware of us except on some negative way as another tier of bureaucracy, not convinced we have exfundholders fully on board, looking forward to greater lay involvement when we go to PCT status, but will we lose GPs'

A continuing theme was uncertainty of the role of lay member, with some informants identifying a long learning curve particularly in relationship to medical/organisational jargon, which hampered participation. The time commitment and workload relating to such participation was also identified. Many informants stated that their involvement had led to excessive hours, more than 2.5 days per month allocated for the role.

> LM258: You may be interested to know that I am disabled and a part time wheelchair user. As I do not work I have plenty of time, if I stuck to the recommended 2.5 days per month very little of the above would be achieved.

> LM287: The description and duties of the lay role are grossly underrated regarding the time needed; the time suggested for a month's duty is the time most lay members spend each week.

The feeling of being isolated as a single lay member was a theme that many informants identified (see Section 8.2.1)

> LM477: In general lay members are still unsure of their role on PCG boards and often feel isolated. If the board consists mainly of clinicians – promoting patient partnership and carers strategies can be a struggle.

Previous Experience

Informants also identified their previous experience, such experiences were often related to their present role e.g., community involvement and/or voluntary work. Some of the types of roles related to specific institutions such as parish councils, school governorship, fire service, justice of the peace, others focused on work within voluntary organisations and/or community development projects. Again supporting

comments made in Section 6.2.5, regarding a public duties circuit (Davies 2001:i) and reflecting similar results to Klein and Lewis (1976:69).

> LM417: Have spent most of my working life in voluntary work, justice of the peace, OU Hons. Graduate, former Chairman of Community Health Council, Chairman of school governing body, trustee of charity etc.'
>
> LM524: Member of the CHC for 14 years, voluntary sector representative on JCC for a number of years, also involved in HGS service …'
>
> LM523: I have worked for over 20 years as a development officer for social services working with client groups/self help groups. My last 2 posts have been with 2 local CVS, I am chairperson …'
>
> LM494: I do have roles in the voluntary sector, trustee of national charity, justice of the peace, governor of school …'

Negative Aspects of Lay membership

During analysis of the further comments, it became evident that some lay members were highlighting particularly negative experiences (8.5%). Such negative experiences moved beyond the established areas identified within content analysis such as isolation, pressures of time or workload. Negative experiences focused on exclusion, lack of role and disillusionment – this area was developed within Phase Three of the research project (see Section 8.2).

Summary

The national survey presented one of the most comprehensive profiles of lay members within PCGs, with a response rate superior to other studies within this area (see Smith et al 1999a, Democratic Health Network 2000, James and Willitts 2000, Davies 2001). The results revealed a relatively unchanged profile in relation to ethnicity, age and occupational background, with similar results found over thirty years ago in studies such as Klein and Lewis (1976). Lay members continue to be unrepresentative of their local communities, suggesting an unchallenged status quo. Furthermore, the relative invisibility of minority ethnic groups and younger people means these voices remain unheard or at the very least under represented.

Furthermore, there are issues relating to visibility of the lay position within the new primary care organisations. The survey showed that a large minority of members were aware of forthcoming positions on PCG boards through established relationships and networks with the service, which brings into question the advertising strategies for such positions. These positions need to be more visible to a wider public.

Paradoxically, once appointed lay members also experienced issues of invisibility with identified difficulties with the lack of job description and adequate training. Themes of visibility and invisibility are developed further within Chapter Nine.

However, lay members engaged in a wide diversity of roles, the majority participating in public involvement, with 50% fulfilling the policy vision of leading in this area. With training identified as non-existent or non-specific, there was a potential to rely on previous experience; aspects of such experience were identified within the survey, which suggests a potential deficit in crucial areas such as community development and inclusiveness. However, the majority of comments from the questionnaire were positive, supporting the view of personal benefits associated with involvement identified in such documents as 'Involving Patients and the Public: A discussion document' (DoH 2001c).

Following data analysis of the national survey, a number of areas were identified for further development within Phase Three of the research study. These included lay members who had taken the lead in public involvement and those members who had particularly negative experiences within their role. Some comments made by informants at the end of the questionnaire also highlighted the difficulties with lay members being over researched. Part of the criteria selection for Phase Three was to include only lay members who were not involved in other associated research projects.

CHAPTER SEVEN

Case Studies

Introduction

This chapter presents the data analysis from descriptive case studies, which formed Phase One of the research project. Two Primary Care Groups were involved in a two-year case study - involvement lasting from October 1999 to October 2001. The two PCGs were chosen as typical sites (Schofield 1993) (see Section 5.6) and selection criteria focused on a conventional board structure, with the organisations operating at Level 2. Three specific methods of data collection were utilised: - observation, interviews and documentary analysis. The data analysis is presented under the headings of Case Study A and Case Study B with Section 7.14 providing a comparative summary between the case studies.

7.1 Case Study A – Area & PCG Profile

The PCG was situated in one of the three boroughs served by one local health authority, all boroughs reflected high levels of deprivation. The PCG was an inner city/urban locality and had a higher proportion of minority ethnic residents than the national average, as well as a substantial number of vulnerable and social excluded groups – unemployment in the borough stood at 13.7%. The health profile revealed high levels of sexually transmitted and infectious disease with higher than national average teenage conception rates and mortality rates. The borough also reflected high levels of coronary heart disease and stroke, with low levels of screening uptake. Depression and suicide rates were also higher than the national average. A Health Action Zone was situated within the locality, one of the first-wave announced in 1998. The area also included one teaching hospital and Mental Health Trust and one Community Health Trust.

Case study A was one of six PCGs attached to the local health authority and was divided into three neighbourhood localities. It incorporated 24 GP practices and had a population of approximately 138,000. The PCG Board, as stated, reflected a conventional structure: - Chief Executive, GP Chair, 6 GP Board Members, 2 Nurses Representatives, Social Service Representative, Lay Member, Health Authority Non-Executive Director with a CHC representative co-opted as a non-voting member. The PCG operated at Level Two within the duration of the study and was planning to

move to trust status in April 2002. The organisation's mission statement identified a strong belief in partnership and its vision focused on shaping a healthy community. Its local priorities reflected this vision by improving the health of children and young people and reducing health inequalities. The PCG had a budget of £2.5 million and was involved with a merger in early 2000, making it a borough-wide group.

The area reflected a complex picture of involvement both in terms of community, voluntary and statutory organisations. A well-developed voluntary sector reflected over 600 groups/organisations stretching across three boroughs. There were a number of established local forums (e.g., pensioners, mental health, homelessness) as well as health panels, with previous use of citizens' juries and on-going citizen panel. There were a number of on-going projects relating to urban regeneration and community development and the Health Action Zone programme reflected Sure Start initiatives. There were plans for a Health Living Centre in one of the neighbourhoods and the PCG inherited established initiatives such as Patients as Teachers and the Expert Patient Programme.

7.2 Public Involvement Strategy

The strategy went through a series of re-drafts before its final emergence as a formal document presented within the Three-Year Plan (1999 – 2000). It reflected a broad overview on user and public involvement, re-iterating established definitions and key principles such as accountability, accessibility, inclusiveness and joint working (see Appendix 11). The strategy echoed a very pro-patient and public stance, '…we believe that the views and ideas of the people whom we serve are central to our ability to achieve our hopes and aspirations for improved health care and better health generally …'. However, it remained very much a statement of intent, as there was little detail evident. Although process was acknowledged, there were no specific objectives, which compromised its ability to monitor and evaluate such involvement. Its aim was to identify objectives from both the Annual and Three-Year Plan. Some broad initiatives were visible with the yearly action plans and they became the main thrust of the research, these included: -

- Conferences relating to health improvement,
- Patient participation groups
- Health needs assessment

- Public consultation for PCT status

Emphasis was placed on public involvement initiatives initiated by the PCG Board and I decided to track events that focused on the involvement of the wider PCG population. Following the merger in 2000 with a PCG in the north of the borough, this research study remained focused in the original PCG area and constituents. As with Case Study B, there were a number of staff changes during the study. The first lay member of the governing board (Lay member 1) became the second Chair of the PCG (Chair 2) and a second lay member (Lay member 2) formerly from the north of the borough became prominent in observations and discussions on public involvement. They are identified as such within subsequent sections.

7.3 Public Involvement Initiatives

Stakeholder Events

There were two Stakeholder Events held by the PCG, one in July 1999 (launching the Annual Plan) and the other in March 2000, where the draft of the Three Year Plan was presented. This was an extensive document offering a matrix of care, which included client and disease groups (see Appendix 12). The CHC representative spoke at the event suggesting that the PCG approach to public and user involvement was excellent, however it was time to '…get out and do things …' (Source:Fieldnotes) that views needed to be shown to have influence. The format of the stakeholder event was to be duplicated with Health Improvement Events and PCT Consultation with professional presentations followed by workshops (see Sections 7.3 & 7.4). The event had time management issues, the workshop groups (which included areas such as poverty, coronary heart disease) were self-select, but they were poorly facilitated and hurried, discussion often moving away from the main focus and were multi-agency dominant.

However, the groups were able to identify gaps in the matrix and give some priorities. The Three-Year Plan gave public involvement some prominence. Within the matrix of care there was strong focus on responsive services, publicising health initiatives, joint working, health promotion, support and inclusiveness as well as staff training. Some of the areas paralleled, and to some extent replicated, a report later on in the year produced by the Public Involvement Coordinator. The lay member attempted to pull public involvement areas (36 items) into a work plan of the Community Participation

Group (see Appendix 13). However, the matrix reflected an unrealistic timeframe and did not address capacity and resource issues with the majority of items left unrealised within the period of the research.

Community Participation Group (CPG)

As with many Primary Care Groups across the country (see Section 6.3.5) Case Study A developed a subgroup to facilitate public involvement. The first formal discussions regarding this group took place in November 1999 and its first meeting was held in January 2000. Although the group had notable successes, particularly, in relation to the planning and running of two health improvement events, internal and external reports and discussions identified its lack of proactive stance. My observations of the group saw an increasing emphasis on information updates and presentations over the two years, supported by agenda analysis (see CPG Matrix for an analysis of the group's development and influencing factors).

It was sidelined, in terms of PCT development and new public involvement structures, with a separate work stream developing, which was management-led gaining responsibility for public and user involvement. At times it was used opportunistically for research purposes; documents such as patient advocacy leaflet, primary care-led commissioning, website development where presented to the group near end completion, with limited feedback time given. Finally it was renamed as an advisory group in November 2001 with its purpose openly bquestioned by PCG personnel leading to the recommendation that it should either be disbanded or incorporated into a PCT work stream. The group's development is analysed further in Chapter Nine (see Section 9.4) identifying the power issues relating to its lack of action.

CPG Matrix (Figure 6)

TIME LINE	PRIMARY CONTENT	ORGANISATIONAL CHANGE	GOVERNMENT POLICY INITIATIVES/DIRECTIVES	KEY PERSONNEL CHANGES	NUMBER ATTENDING	PROVIDER/PUBLIC RATIO	VENUE	GENERATED PUBLIC INVOLVEMENT ACTIVITY	FUNDING
Jan-00	First Meeting Shared vision Terms of reference Examples of community participation	Discussion of potential merger		Partnership Development Manager employed to work borough-wide	22	11 Service Providers attending meeting 11 Members of the public attending meeting	Health Centre - First Floor	Policy review - Commissioning	No ring-fenced budget identified
Mar-00	Terms of reference Naming group Feedback from commisssioning consultation HAZ funding for patient participation Information exchange	Merger Identified	Merger related to forthcoming move to PCT status		18	6 Service providers 12 Public	Conference Room Local Hospital First Floor	Work group to be developed to plan and implement HYSD - Older Adult in September 2000.	HAZ Community Involvement Funding £7000 per PCG
Jun-00	Research for Change HAZ funding Have Your Say Day Naming Group Information Exchange		Central funding available in relation to social exclusion, the elderly and mental health Call for research bids		19	11 Service providers 8 Public	Conference Room Local hospital 2nd Floor	Regular section for public involvement in PCG newsletter	
Jul-00	Borough-Wide Community Partication Subgroup PCT and Public Involvement Update Research for Change HYSD HAZ funding Infomation exchange	Merger completed Borough-wide Community Participation Group establisedhed	PCT consultation NHS Plan and Chapter Ten	Duplication of staff following merger 2 governing Boards & Board members	11	7 Service providers 4 Public	PCG Headquarters Locality 2 (North Borough)	Lay member to prepare annual report on CPG activities for September PCG Board meeting HAZ funding to be used for six-month position of Public Involvement Co-ordinator	HAZ funding £15,000 per PCG for public involvement consultation
Sep-00	HAZ funding Patient Particpation Groups developmen PCT - update on current position Plans for the future Group discussion on PCT status and public involvementl nformation exchange				18	13 Service providesr 5 Public	Medical Centre (1)		
Nov-00	HYSD briefing. NHS plan Annual user and public involvement review PCT and public involvement Patient participation groups Future direction of the Community Participation group Draft workplan			Public involvement Co-ordinator employed on a six-month contract Chief executive (South Borough) stopped attending CPG meetings	18	11 Service providers 7 Public	PCG Headquaters - Locality 2	Working group for HYSD Mental Health formed for a conference to be held in April 2001	
Jan-01	News updates PCG website Public Involvement Impact statements Patient advocacy forms Medical information in lay language Workplan to October 2001	Six month public consultation for PCT status starts in February 2001 12 Workstreams developed within the PCG focusing on the move to Trust status - no pulbic involvement workstream		Lay member becomes Chair of the PCG	25	16 Service providesr 9 Public	Medical Centre (1)		
Mar-01	Future chair and vice chair for CPG Updates on impact statements Patient advocacy leaflets Patient participation groups Research presentation PCT development workplan comment and ratification				16	11 Service providers 5 Public	Medical Centre (2)		
May-01	PCT status - Report presentation (Voices from the Community by Public Involvement Co-ordinator) Report on HYSD Report from Voluntary Organisation Health Heart Day Update		PALs	Community Development becomes Chair of CPG, Lead from PPG2 becomes Vice Chair	17	13 Service providers 4 Public	Civic Centre		
Jul-01	Feedback from PCT public and user involvement workstream Feedback from PCT voluntary sector workstreams Comments on the role of the group HYSD (mental Health) Sexual Health Provision, Patient participation	Public and User Involvement Workstream developed by PCG Board, led by Chief Executive (North Borough) CPG not involved with this development Public Consultation for PCT Status completed	Local Modernisation Review Shifting the Balance of Power		15	10 Service providers 5 Public	PCG headquarters - locality 2	CPG involved in Visioning Exercise regarding PCT status in September 2001	
Nov-01	Presentation (UHL Phase 3) Presentation UHL draft strategy for public and user involvement. Patient participation groups updates Presentation on public involvement Public user involvement workstream group update	Community Participation Group re-named as Advisory Group by PCG personnel	National Health Service (NHS) Reform & Health Care Professions Bill	Full-time position for public co-ordinator established Position filled in September 2001 - resigned in Novemeber 2001	18	12 Service providers 6 Public	PCG Headquaters - Locality 2		

198 198 198 198

Health Improvement Events

Four conferences/workshops were originally planned as public consultation exercises based on HimP priorities – the older adult, mental health, sexual health and coronary heart disease. This initiative was introduced to the CPG by the Chief Executive in March 2000 and some group members were directly involved with its planning and implementation. Each conference was estimated to cost £6,000, the research followed two conferences – older adult and mental health – both taking place between 2000 and 2001. With the first – older adult – the conference recommendations were tracked until June 2002 to evaluate the impact and outcomes of the consultation. The second – mental health – the main focus of study was the planning and implementation of the conference.

The Older Adult conference and six pre-defined workshops were held in September 2000, a working group (n=23) was formed from attendees to ensure that action was taken on conference recommendations. There were 28 original recommendations, which were wide ranging and would have required a multi agency approach to address them adequately. Following multiple postponements and reschedules, the first working group meeting was held in March 2001. The recommendations had been reduced from 28 to 9 by PCG personnel, 7 out 9 were general practice related. 13 people attended the meeting and despite the focus of the following recommendations (see below); the group did not include general practitioners, community nurses or practice managers.

- Over 75 screening
- 15 minute appointment times for older adults
- More home visits
- GP communication
- Drug rationing
- Multi-lingual skills

Although the group members were unhappy regarding the reduction in recommendations, the two-hour meeting focused on the remaining nine. As an experienced practitioner I was interested that the discussion did not touch on the resource issues of screening all patients over 75 or increasing home visits, nor the equity issues relating to increased appointment times based on age rather than need. There were some stereotypical views of doctors and nurses evident, the meeting

progressing with personal narratives of poor experiences of general practice. In a two-hour meeting that would only be held six monthly, this left little time for the group to be proactive in relation to the recommendations. A final draft of the Conference Report was circulated to all attendees, facilitators and Board members. Progress was reviewed at a group meeting in June 2002, discussion still focused on potential action at this time and no recommendations had been implemented. The meeting again showed evidence of personal narrative and the revisiting of issues, some discussion areas did not relate to the recommendations at all (Appendix 14).

The Mental Health Conference was held in April 2001 with 100 attendees, with primary and secondary care health professionals and social care workers meeting the public and service user representatives in an open forum. The objectives for the conference were broad and conference developers described it as '…one of the most ambitious and innovative public involvement exercises of all time'. A small planning group, made up of CPG members and community development workers devised the content - posters and leaflets were circulated widely.

The structure of the day conference reflected staff presentations, workshops, performance artists, lunch and feedback to panellists. The staff presentations over ran their allocated time, a characteristic of many of the public conferences attended, which ate into consultation time (30 minutes). Furthermore, the quality of presentations was poor e.g., no or inadequate presentation aids, the use of medical terminology such as 'forensic' 'sectioning' as well as the use of professional narrative '…the service is under huge strain…' (Source:Fieldnotes) focusing on pressure and caseload. Some of this material could have been presented in the lobby as an exhibition.

There were six workshops: -

- Mental health and primary care
- Hospital services
- Mental health and race
- Mental health and young people
- Mental health and the elderly
- Moving on and support for users and carers

There was no workshop on mental health and women and I joined a workshop on mental health and primary care, facilitated by GP Board member. This was a realistic discussion, which was well facilitated with a multi-agency feel, however no nursing services were involved with a predominant focus on general practice. 20 attendees signed up for the 'follow up action group' and the day generated 12 recommendations. However, one GP board member noted that these recommendations were not part of the National Service Framework and therefore it would be difficult to keep them at the top of the agenda (see Appendix 15). The Mental Health Group (GP led) were to respond to these recommendations. The evaluation was formative (Beresford and Croft 1993) and strongly focused on the success of the day e.g., the conference had increased confidence levels, there was evidence that secondary care services were being reassessed, with suggestions on future actions (see Appendix 16).

Following two conferences, the focus on large processes was re-assessed with the decision that no further conferences took place. Sexual health accessed existing community projects. This incorporated a sexual health questionnaire and the profiling existing services. The aim was the development of more systematic services and the introduction of reproductive health clinic. There was also a Healthy Heart Day in June 2000, this included stalls and workshops with 200 people attending (99% expressed satisfaction with this event). The initiative was developed by the PCG Coronary Heart Disease subgroup to meet NSF responsibilities, with no input from the CPG.

Newsletter

This was distributed to GP practices and service users and was a developing format, which moved from a photocopied product to being a professionally printed article by September 2001. Although the newsletter had a wider circulation than Case Study B, analysis of the publication suggested that it was still very much focused on professionals and practice staff. Much of the topics focused on staff changes, clinical governance, prescribing and IT development. Patient and public involvement, if discussed, tended to be near the back of the publication. However, there were useful updates on PCG developments and community initiatives, particularly, in relation to PCT status as well as bids and acquired funding.

Practice Level Initiatives

Two Patient Participation Groups had become operational before accessing the site. during the case study there was no further development of groups within the south of the borough (2 out of 24 practices). Although there was discussion that there should be a Patient Participation Group in every surgery, this was not forthcoming within the duration of the study. Furthermore, this suggestion did not reflect the public involvement strategy at the time, even though there was available funding to support their development from the local HAZ. Although not a direct PCG initiative, both PPGs leads attended CPG meetings and the decision was made to follow their progress. The groups supported Bray and Richardson (1987) research cited in Brown (1999) as both were GP initiated.

1. Patient Participation Group A

The practice manager and senior partners were involved with the selection of individuals for the group. Selection was not random and specific patients were approached regarding membership. The criteria focused on candidates that would be proactive rather than have 'axes to grind' as well as balanced in age, ethnicity and gender. Initially, the practice manager identified that there were problems with the group size and poor representation from male members, however the group was to become extremely proactive during the study, growing to 20 members. The group was chaired by the senior partner in the first year and supported by the practice manager and a senior receptionist. The lead of the PPG was a very proactive individual and became a member of the Community Participation Group in 2000. In a series of interviews the progress of the group became clear.

The group constructed a patient satisfaction survey and interviewed 450 practice patients in January 2000. The questionnaire focused on satisfaction levels and 'what would you like to see' and there were also open-ended questions about getting involved. This reflected a usual function of patient participation groups who often focus on feedback about practice organisation (Richardson and Bray 1987 cited in Brown 1999). This led to a number of small changes – a system for patients to use the phone and play area facility.

However, the group gained funding for complementary medicine and stress management courses that where subsequently initiated. As members got more involved, the group wanted to develop a set of aims and priorities and decided to look at other PPGs - such as a purpose built practice with a strong emphasis on complementary therapies. The group developed a written constitution with the support of local voluntary action organisation and was thinking of charitable status to help with bids for funds. The group did take the decision to become a voluntary group and was renamed 'Patients in Partnership', doctors and practice manager did not have voting rights.

The group had been involved with paid presentations such as the Group Practice Managers forum. One person within the group was an expert in fundraising and the group were focusing its energies on bids and selling services. A GP attended every meeting, which provided an opportunity for the doctors to tell them about new initiatives and to seek support. Conversely, the Chair was invited to monthly practice meetings; there was no involvement in clinical governance, audit or complaints procedure issues or joint initiatives, however, she noted 'we are pushing the boundaries'.

The lead found GPs at this practice supportive and the practice manager responsive. An interview with a GP in PPG A, identified that he would like the PPG to get involved on a strategic level, perhaps with a PMS pilot. Indeed, the practice reflected the pro-active stance identified in research by Brown (2001), which suggested that practices which valued teamwork and viewed themselves in a broad social role were more likely to engage with the public. The lead also identified that there was going to be involvement by a local university with students in complementary therapies involved in the sessions under supervision. Areas under development were workshops and seminars on other health issues, also self-help aspects, such observations tended to suggest that PPG A moved beyond the average functions of such groups (see Brown 1999).

2. Patient Participation Group B

The patient participation group started in November 1999, the practice was single handed with one partner and one salaried GP. Again the group was GP initiated and

the lead was approached to see if she was willing to co-ordinate a group, her experience as a long-term carer bringing her in contact with the surgery regularly. At the first meeting other people were targeted and there were 6 patients and 2 GPs within the group. There was a discussion about drawing more people in and the group being more representative, successful strategies focused on informal networking or a direct approach by the GP, advertising in the surgery had not worked. The group had insisted on item agenda - the GP updating on any new developments. The GP and practice manager usually attended meetings but not always. The group was given a small annual allowance for administration.

Again, the group produced a Patient Satisfaction Survey and is construction and administration was supported by the lead of PPG A. A public involvement facilitator at the health authority critiqued the questionnaire and approved its deployment. However, limited support was given in analysing and presenting the results, a lot of personal time had been taken up in this process, something that she discussed in a CPG meeting. It was the first time she had constructed a questionnaire and would have liked word processing training as well as support in chairing. Changes were implemented following the survey, with earlier surgery two days per week and a walk-in clinic every am and pm. The group had produced a newsletter; again this was home produced and the lead found formatting difficult. The second newsletter was based on comments from the survey enabling the GP to answer some of the generated queries. Again the lead did not feel very supported in this initiative. The practice also had a suggestion box and at the time of interview, the GP and lead were developing written information to complement patient consultations. Discussions in July 2001, found the lead having difficulties with facilitating the group and sharing out responsibilities to group members.

The lead of PPG B was also a member of the CPG from its inception and continued to play a consistent and active part within group activities, becoming vice Chair in 2001. However, she noted that there was no clear plan on how PPGs were to be developed and there were difficulties with the monitoring and evaluation of groups within the south area. This may suggest that Case Study A lacked important mechanisms for co-ordinating and monitoring initiatives, identified in Taylor's research (1995) and this is discussed further within the summary (see Section 7. 6)

3. Neighbourhood Groups

The PCG developed a neighbourhood locality structure, '…as a bottom-up approach to the development of the PCG agenda…' (Annual Report 2000). Documentation suggested that such groups were to provide an opportunity for constituents and partners to have a structured role in influencing the delivery of the PCG agenda; indeed, there had been an historical service preference for this approach (see Taylor 1995). However, the agenda for the Neighbourhood Groups were set by the PCG and personnel were a little unwilling to meet monthly. The groups consisted of general practitioners, nurses and practice managers – an interview with a practice manager showed that these groups had been protective of their own practice interests. Through the duration of the study the groups were not open to patients or voluntary representatives.

4. Community Partnership

Also involved at a practice level was a local community development partnership. A local voluntary organisation was utilised by the PCG to undertake discrete pieces of needs assessment with local general practices – serving as a good example of commissioning other agencies in involvement initiatives (Barker et al 1999) and highlighting the importance of the use of community development workers (Crowley et al 2002, Cornwall et al 2003). The group secured 2 years funding for a community worker to support a number of local initiatives - farmers market, allotments and breakfast clubs. Working with four GP practices, they identified the lack of social activity opportunities for young people and were hoping to get funding for another community worker and some social activities were initiated.

7.4 PCT Progression & Public Consultation

The PCG Business Manager led on PCT development and the local Health Authority had a steering committee, which included representation from the six PCGs and the Community Health Trust. Task groups were also developed, which consisted of predominantly health authority and PCG personnel. The main steering group within the PCG was the Organisational Development group and the non-executive director of the health authority chaired. This group guided the strategic direction of the PCT, developing a vision for the new organisation using the results of local visioning exercises – a PCT Action Team was established to oversee 13 work-streams. The PCT

Action Team included the two Chief Executives, two Borough Directors and project manager.

A work-stream for Public Involvement was only established in July 2001, perhaps reflecting its priority and although the CPG was involved in a visioning exercise, it was not involved with this work-stream. However, the partnership development manager (CPG group member) was involved and the work-stream focused on the development of PALS and a community development strategy. There was also a work-stream focusing on PCT Board development, which provided additional local guidance on the requirements and selection for non-executive directors on the new PCT Board. There was a strong focus on representation as the group wanted to reflect the diversity of the community as well as an effective mix - a group member consulted with the CPG and different community groups regarding this. The PCT Board work-stream was extremely proactive in promoting these new lay positions, this included wide distribution of a specific leaflet 'Opportunities as Chairs and NEDs' as well as press advertisement and open sessions held in June 2001. The outcome was a good amount of applications, however, not number specific.

There was a six-month consultation period from February to August 2001 and the role of voluntary organisations was highlighted within PCT publications i.e., to contribute views and experiences to PCT decision-making, develop partnerships with the PCT, to provide services and improve health. Consultation took the form of a series of visioning exercises, a public consultation/workshop, public meetings and focus groups.

1. Focus Groups

The local voluntary umbrella organisation suggested that it was best placed to run and organise events that were relevant to their members and users. The result was a series of six focus groups with specific service user groups (homelessness, disability, ethnic minority, children, deprived neighbourhoods, refugees). Analysis of such user groups suggested that the case study did attempt inclusion by placing emphasis on groups who, historically, have had limited involvement with health services (see Murray 1999, Stewart 1999). A researcher, with previous experience of developing links with the voluntary sector, was commissioned to conduct the groups and produce a final

report. I decided to observe two of these groups – homelessness and refugees, the former had only 4 attendees and the latter none. This was also reflected with the four remaining focus groups even though 13 or 14 representatives were asked to each group. The umbrella group identified the organisations, in discussion with the researcher, she suggested that the problems with attendance were that groups were too busy, with too many meetings; the focus was '…immediate rather than something next year' (source:fieldnotes). It also suggested that the PCG had selected an inappropriate involvement method and perhaps visiting user groups within the community would have proved more productive.

Despite this, the consultation yielded 11 recommendations: -

- The PCT should operate according to key principles
- An effective public involvement strategy
- Funding for the voluntary sector from the PCT
- Proactive approach to voluntary sector representation on the PEC
- Develop more integrated services
- Health promotion services for people facing access barriers
- Commissioning services from the voluntary sector
- Access to PCT budget
- Develop and monitor service standards for all practices
- PCT should work with voluntary organisations to raise professional and staff awareness of the needs of carers and users.
- Information provision about services and how to access.

2. Conference

A one-day conference was held, which followed a similar format to the Stakeholder and Health Improvement events with professional presentations followed by workshops. The conference was open to all voluntary sector organisations and was held in February 2001, at the Civic Centre, questions focused on 'How can the PCT change or develop services?' and 'Practical suggestions for the PCT from the voluntary sector'. Evaluation of this event again focused on the day and related to venue, refreshments, equal opportunities and the quality of the conference and future issues.

3. Community Participation Group - Visioning Exercise

This exercise took place within the September 2001 meeting of the CPG; the focus was to consider the development of PCTs locally and their potential benefits. Some of the discussion focused on the level of influence the National Plan should have on the development of public involvement within the PCT, with the majority view that the focus should be on development of involvement outside the plan, asking the question 'what people want, what are the positives of the Trust'. The group was then asked to self-select to one of two groups, I joined the group addressing the following question: - 'How public involvement fits into the PCT structure'. A number of areas were briefly discussed and noted: -

- The role of the patient forum
- Developing partnerships
- Communication mechanisms
- Supporting initiatives
- Lines of accountability
- Funding
- Enforcing decisions
- Promoting a culture of involvement

7.5 The Role of the Lay Member

Discussions with the lay member revealed a long-standing interest in health and social care, interest in the position focused on making a personal impact and advocating for more customer-centred services. Previous experience was linked to local authority and charity work and she remained the manager of a small charity whilst working as a lay member, reflecting traditional lay experience (Davies 2001). Her discussion emphasised the need for experience of the health sector.

'A lay member with no experience would be absolutely lost and would not have got through the interview without that experience and knowledge, they don't want a member of the public. Knowledge of the health service is crucial, what is realistically achievable'.

She described the job description as huge and wanted to be involved in everything. over the first year she started to clarify her role. It was clear that she saw her role as facilitative and strategic, rather than leading public involvement initiatives: -

'... bringing people together around user involvement, helping to facilitate process and may be initiating aspects of it and making sure user and public involvement actually does get the proper discussions at board level'

She also saw her role as picking up public views and feeding back, ensuring that the PCG was accountable for public and user involvement. Role development saw the lay member chairing the CPG for 18 months before taking on the role of Chair of the PCG in July 2001. She also represented the PCG on a health panel and wrote the original public involvement strategy as well as involvement in the clinical governance strategy. She had some experience of public involvement methods such as focus groups, workshops and public meetings, however she no training in this area, although she had received a patient and public involvement manual, identified as Barker et al (1999).

She reviewed the Three-Year Plan (1999), identifying areas for potential public involvement as well as reviewing the progress of the CPG in its first year. The development of her role to Chair shows an acceptance by other Board members, however she admitted her ability to be actively involved in public involvement issues was reduced after taking this position. Within the two-year case study, she accepted a position with the CHIQ, acknowledging that the experience of being lay member had focused her interests on health issues, which disqualified her from applying for the post of non-executive director within the new PCT.

7.6 Case Study A Evaluation - Perspectives on Public Involvement

Meads (1999), within his research on PCGs, produced a typology with four discrete organisational types, formulated from the analysis of organisational objectives, management structure, health strategies and internal and external relationships. Case Study A reflected many of the characteristics of the 'friendly association'. The proposal of PCGs was accepted and extensive involvement was encouraged. However, Meads (1999) warned that problems could occur in relation to operational

efficiency and effectiveness, an inclusive approach could be time consuming and financially demanding. Aspects of this description can be seen in the PCG's openness, general enthusiasm for community involvement and its keenness to initiate public events, however planning and overall effectiveness were questionable.

Profiling & Audit

Although area profiling was discussed in November 1999 this was not carried out, nor was an audit of previous/on-going consultations, despite being identified as crucial within supporting literature and research (see National Consumer Council/Service First Unit 1998, Barker et al 1999, DoH 1999a, NHS Executive Northern & Yorkshire Region 1999, South 2004, Fawcett and South 2005). Different statutory and voluntary organisations had information/databases regarding public involvement initiatives, however this seems to have been neglected by PCG personnel. The public involvement co-ordinator's review of previous consultations carried out much later in 2001, showed the importance of collating previous material, which generated substantial recommendations. Furthermore, inadequate local intelligence had led to costly errors. For example, the Health Improvement Event (Older Adult) had attracted 55 attendees, however a week before there was a meeting of the pensioners' forum, giving access to a much larger number of potential informants. Citizens' panel and established forums seemed under-utilised as methods of involvement. Unlike, Case Study B, the PCG, at times, failed to take full advantage of existing involvement structures (see Barker et al 1999, Crowley et al 2002), latterly, lessons were learnt as plans for the final two large process events were cancelled and small-scale events and surveys took their place. The problems with gathering local intelligence were highlighted by a number of CPG members: -

'...we didn't know it but they were things that had been done...' (Partnership Development Manager)

'...having that intelligence about the community, who is there, who is involved, what they want, what they need...' (Voluntary Sector Representative)

Personnel & Expertise

The importance of employing a dedicated person for public involvement (see Taylor 1995) was obvious from the impact of the public involvement coordinator over his six-month period in post. As well as producing a report and facilitating training sessions with practice staff, he was able to recognise the importance of going out to voluntary agencies and networking – this included a visit to an established PCT. He was able to provide a future vision on public involvement within the Primary Care Trust, suggesting relationships with patient forums, PALS and locally established initiatives (see Appendix 17). However, an analysis of his job description suggested a lot to do within a limited amount of time! (see Appendix 18). The intermediary periods left a vacuum of responsibility, lines of accountability remained unclear and this impacted on the direction of the CPG and left members of patient participation groups feeling unsupported at times. Again discussions with key personnel identified the importance of a full-time position.

'I would have liked to have seen a full-time public involvement co-ordinator from the word go…' (Lay member 1)

Discussions with the partnership development manager again highlighted difficulties with broad job descriptions and capacity. The partnership development manager worked across both PCG areas before the merger had two bases and was responsible for developing partnership initiatives between the PCG, local authority and voluntary sector. This included regeneration and community development, joint planning, commissioning and fundraising. Public involvement was not part of the remit, however there was an explicit expectation regarding her participation in this area, even though she had limited experience of initiatives or pertinent literature.

'…everything to do with user and public involvement came to me when I first came, even though it wasn't even in my job description'

Within the membership of the CPG was identifiable expertise in public involvement, which was either under-utilised or mismatched, perhaps again the problem with lack of auditing, important in assessing organisational capacity (South 2004). This included an assistant director in public involvement, HAZ public involvement

facilitator and highly experienced public involvement coordinator from a NHS Trust as well as a GP board member with extensive publications and proactive in public involvement initiatives at practice level. This expertise remained to a greater extent untapped, whilst an outside consultant highly experienced in bidding and fundraising lead on the development of a large process event in which she had no previous experience. Furthermore, the lay member did not lead in developing the public involvement agenda and her role was further compromised when she took the Chair of the PCG.

However, voluntary sector representatives did take an active role in developing and implementing initiatives, accomplishing needs assessment with four general practices. It also served as an example of the importance of going out into the community itself to elicit views. PCT development benefited from the involvement of the non-executive director of the health authority, whom had been a PCG lay member. Eventually, a full-time position for a coordinator was filled in September 2001, however the person left quickly and abruptly – one reason for resignation related to cultural difficulties focusing on the transition from the voluntary to health sector. Such difficulties highlight the need for cultural fit and a strong organisational awareness in perspective candidates as well as developed impact and influencing skills. The result was that the money for this position was immediately reallocated.

Strategic Development

As with many PCGs researched (see Section 8.1.4), the lay member was responsible for the development of the public involvement strategy. Although accepted at board level, a number of evolving issues suggested that strategic development needed to be a more inclusive and collaborative process. It was clear from discussions with PCG staff, clinicians and community representatives that they held very different perspectives on involvement, resulting in a lack of a unified vision and making strategic development extremely problematic. There was a strong emphasis on community development as a model of involvement. This may have been a reflection of the PCG area and the background of some of the key players, however it tended to marginalise other perspectives and impinged on the development of a comprehensive strategy.

'...I certainly don't feel comfortable just with community development as out public involvement model...' (Chair 2)

The public involvement strategy reflected general advocacy for public involvement as a principle, however the lack of clear and specific objectives meant that the document could not be utilised as an evaluative tool, again a crucial area identified within the literature (see National Consumer Council/Service First Unit 1998, Lenaghan 1999, Chambers 2000). Its link to the Three-Year Plan, which identified 36 areas of potential involvement, again lacked specifics related to outcome, priorities and timeframe and, therefore, proved unrealistic.

Methods of Involvement

The PCG initiated a number of public involvement methods: -

- Website Development
- Newsletter
- Community Participation Group
- Subject specific one-day conferences and linked workshops
- Healthy Heart Day
- Sexual Health Questionnaire
- Health Needs Assessment – outsourced to local voluntary organisation
- Focus Groups

An evaluation of above methods would tend to support Lupton et al (1995) assertions that organisations do not include a full range of different types of involvement. In terms of power sharing and empowerment the methods continue to reflect evidence of tokenism (see Arnstein conceptual framework (1969) in Lupton et al 1998). The strong emphasis on large process events suggested this was the preferred method of the organisation (Taylor 1995) and there certainly was previous historical context in relation to conferences. However, the conferences were costly and perhaps not enough time was spent discussing whether this was the most appropriate strategy. Interviews with the outside consultant and public involvement coordinator identified the importance of 'leg work' going out to organisations to develop trust, networks and gain information, this approach perhaps needed to utilised to a greater extent.

Lack of Focus on General Practice

As previously discussed, the majority of recommendations from consultations related to general practice and community nursing services, however there was a low level of practice development throughout the two-year case study and lack of active input from these professions within the CPG itself. The neighbourhood groups remained exclusively the domain of professionals and were perhaps a missed opportunity. The lead of PPG B identified a lack support from the PCG, a concern also highlighted by the lay member and the chief executive. Input of both PPG leads continued to be low on agenda items within CPG meetings. The question remains that if the PPG leads had been encouraged to discuss their results and concerns within the CPG on a sustained basis, greater support and advice could have been offered. Both leads identified that the National Association of Patient Participation guidelines for setting up groups had not been useful and were developing their own start up pack.

However, PPG A was extremely successful and had developed beyond a fundraising mechanism, becoming a voluntary group with a written constitution with restricted voting rights. Although a GP initiated group, the participants had developed their own survey and had implemented patient recommendations, this moved beyond small changes to the development of complementary sessions offered at the surgery. It was one initiative that seemed to move towards a model of participation, with patients making decisions (See Arnstein's Conceptual Framework (1969) cited in Lupton et al 1998). The context certainly aided this development; this was a large multi-partner practice with a senior partner that was very proactive. Less dramatic results were seen at PPG B, which was single-handed with no purpose built building, findings duplicated in Brown's (1999) review of PPGs. However, the lead of PPG A did suggest that there were 'many ways of participation' and emphasised the need for different mechanisms at practice level. Interestingly the success of PPG A resulted without the direct involvement of the CPG or PCG itself, agenda analysis showed little time was given to highlighting its work as a pro-active model (see Section 9.8 for further discussion).

Organisational Capacity

The development of public involvement should be paralleled by organisational development, building capacity with the ability to deal public responses and

recommendations (Christie 2000). It was clear that the PCG lacked certain essential mechanisms this included an effective communications strategy, which would have enabled adequate feedback and the dissemination of information. There were also difficulties in translating consultation recommendations into actions as well as comprehensive evaluation of initiatives.

The CPG was able to identify a number of actual and potential problems crucial to public involvement and persistently discussed issues of communication e.g., information dissemination (February 2000), linking top down and bottom up initiatives and resulting information together (June 2000) as well as the need to regularly update websites and databases. Discussion about PCT consultation (July 2000) identified the lack of public awareness and the need to broaden publicity. However, problem identification did not led to many obvious solutions and it became clear that there was a lack of a tangible strategy in relation to communication and feedback mechanisms. Again this seems to relate to difficulties in accountability and people taking direct responsibility to action some of these areas. The Business Manager, in discussing the voluntary sector meetings for PCT status, stated '… people do not understand the concept of a PCG let alone the PCT, however, groups still want to feed into policy'. There were similar problems relating to feedback mechanisms, the Chief Executive also identified this difficulty: - '…we don't communicate back to users very well …' and the nurse representative '… there needs to be a mechanism … its not just about complaints but also about how things are going to be developed'.

In analysing reports relating to conference events, planners had included mechanisms to aid the implementation of recommendations, with the formation of work groups to follow progress, a technique also used within Citizens' Juries (McIver 1998). However, the partnership development manager identified users' frustration that recommendations from the Health Improvement Event had not moved forward and recognised the need for the PCG to '…look at what it's doing around mechanisms for implementing what people are saying…'. This suggests that organisational change did not keep pace with involvement initiatives and was unable to provide the responsive structures needed to deal with information and analysis (NHS Executive/IHSM & NHS Confederation 1998).

A report by a GP board member suggested that user recommendations agreed by the Board should be incorporated into routine patient care and performance management. Practices should have devolved budgets and should be able to demonstrate successful implementation. However the report was criticised, as it did not address the new structures PALS and Patient Forums. There were growing concerns of persistent consultation, as the lay member noted '…when do you stop listening and start doing…'. Further attempts were made to move things forward with a number of action plans, however, these were not fully addressed during the case study period.

Lack of Evaluation

Much of the evaluation of initiatives focused on process rather than impact and outcomes, Health Improvement Events and Health Heart Days were assessed as exercises and levels of participation (see Appendix 18). However, the Health Improvement Event on the Older Adult was strongly criticised by a number of community development workers as 'badly organised' and 'poorly facilitated', unfortunately, some PCG staff tended to personalise this criticism. The 'Review of Progress' (April 1999 to August 2000), identified that plans had been 'overly ambitious' and there was a 'lack of understanding', however achievements focused on group development and initiatives rather than an evaluation of such initiatives. The lay member, from the north of the borough, presented an evaluation form in January 2001, although simplistic, it was the first attempt at a formal evaluation tool and included an assessment of the impact of initiatives. The PCG Board accepted by this tool subsequently, however a further interview with lay member (2) identified that it had 'died a death' and had not been utilised.

Consultation fatigue & Re-Iteration

A review of multi-agency events across the PCG area reflected continuing themes of consultation, duplication and re-iteration of key principles. Examples of events were presented to the CPG, such as a Local Compact between the local council and the voluntary sector. Here, consultation had taken 22 months and cost £30,000, although the final report showed action plans it did not provide examples of concrete changes. In June 2000 health authority and health action zone representatives held an event to identify important aspects of public involvement, however key principles relating to involvement are well established and well published (see Appendix 19).

Similarly, a Community Advisor Team was established in June 2000 with a small membership from the voluntary sector, their recommendations re-iterated other consultation events by the health authority, Compact and CPG. Such observations suggested a level of consultation fatigue and a failure in inter-agency collaboration again identified as important (DoH 1997, Dobson-Mouwad 2000); similar findings were highlighted by Anderson and Florin (2000b). Such frustrations were highlighted in the public involvement coordinator comments '… we don't want to keep spending money asking people what they think and we don't use it'. Discussion with the HAZ public involvement coordinator identified that too many people were working on the same problems. An example of this is the duplication of surveys at a general practice surgery – one by a Community Development Group, the other by PPG B.

Achievements and Difficulties

Much of the discussion on achievements relate to a growing awareness of its importance. The partnership development manager suggested 'It's there and it's visible and I don't think it was when I started', this was re-iterated by the lay member (Chair 2) '…there's an open door now rather than banging on the door …'. However, discussions with the Chief Executive highlighted the sense of a missed opportunity '…we've done a lot, but at the same time I kind of feel we haven't done quite as much as we aspired to …'. Other areas focused on the identification of funds for a full-time position for a coordinator and the development of patient groups and devoting resources to consultation exercises. The PCG was beginning to address cultural issues and the experience was seen as a good learning exercise for the PCT, however the impact of involvement seemed less tangible - 'I can't think of very many specific improvements…' (GP Board member)

The national agenda was persistently linked to difficulties in developing local public involvement initiatives. The Chief Executive discussed the pressure on the system from government directives and the impact of National Service Frameworks, National Carers Strategy, Patients Forum and PALS. This was emphasised by the lay member (Chair 2) '…so many of the national must do's have kind of skewed what the agenda might have looked like…' Capacity was also seen as a major difficulty and highlighted by other research projects (see Anderson and Florin 2000b). The GP Chair (1) found the position time consuming, impinging on personal commitments.

Similarly, the representative of an umbrella voluntary organisation identified difficulties, with no one to deputise she did not have the capacity to be involved in everything. The partnership development manager linked the lack of capacity for the reason why work plans were not revisited and the lack of task allocation 'if I'd more capacity I would have done more work'.

Training was characteristically sporadic, opportunistic and dependent on available expertise and funding (also highlighted in associated research by Bond et al 2001, South 2004). As Chambers (2000) suggests poor training can lead to questionable consultation and inadequate skills were identified within initiatives. Observations from a variety of conferences suggested persistent difficulties with time management skills, all presentations ran over reducing the active consultative period significantly. The quality of those presentations were extremely variable, sometimes lacking visual aids or where utilised to emphasis the stresses and pressures on services. Meetings were often poorly facilitated, with too many agenda items, general debate and discussion was allowed to continue for long periods suggesting the need to address chairing skills. Again many of the board members identified little specific training, although, some GPs had self-initiated sessions.

Some difficulties were more fundamental relating to 'who' and 'how' to involve: - '...I am not convinced that in the year that we've been looking at user and public involvement that we have really genuinely tapped into the general public …' (Lay member 2). Another voluntary representative identified physically not knowing who to go to and when to involve, this had led to a acknowledged focus on current users. Cultural and ideological issues were also highlighted - 'There's no reason why we have to take it seriously, no pressure to do it, no audit – it remains a kind of aspiration' (GP Board member).

7.7 Case Study B – Area & PCG Profile

Case Study B was situated within a suburban/semi-rural area within the South East region, the Primary Care Group incorporating two boroughs within its configuration. The county reflected a high-income area, with a high level of owner occupancy, low levels of overcrowding. Although there were pockets of deprivation within the PCG area, with particular groups that experienced disadvantage and social exclusion. The Department of Employment Index of Local Conditions ranked the two boroughs lowest in the county, with unemployment higher than the county as a whole (5.2% in comparison to 1.9%). Within the PCG area, 8% of the population are over 75 years, 6% were under five and 2.8% from black and ethnic minority communities. The health profile reflected smoking, alcohol consumption and sedentary lifestyle above the national average. However, mortality, cancer, heart disease and stroke rates were all below the national average.

The PCG was one of seven within the local health authority, serving a population size of 154,000 and covered 22 GP practices. The board presented a typical structure with 7 general practitioners, 2 nurses, 1 social service member, 1 chief executive, 1 lay member and 1 non-executive director with the GP as Chair. The PCG at the beginning of the study was operating at Level 1, however, quickly moved to Level Two in November 1999, with a devolved budget of almost £3 million pounds and was planning to move to trust status in April 2002. Importantly, there were a number of board member changes during the research – both GP Chair and Chief Executive positions gained new personnel in 2000. This is reflected in examples of transcripts with the use of GP Chair (1), GP Chair (2), Chief Executive (1) and Chief Executive (2).

There were two Community Trusts and two acute hospitals managed by a single Trust within the PCG area. The PCG provided and commissioned care for almost all people within the two boroughs, with boundaries co-terminus with social services and borough councils. As with Case Study A, the PCG developed into geographical localities, this time four, based on natural communities and GP premises. Local priorities focused on reproductive health and the reduction of falls by 20% by 2001, with much of the health improvement initiatives relating to registers on mental illness, risk, CHD/stroke and cancer.

Both boroughs had established involvement structures, a joint initiative with the health authority, local NHS trusts and voluntary services. Seven forums had been developed in 1997 within in each borough, acting as a conduit for voluntary sector, carers and users views, which fed into a Community Care Planning Partnership group. The forums reflected local service structures and community/support teams and were defined in terms of client and disease groups: - elderly, physical and sensory disabilities, mental health, carers, children with disabilities, children and families and people with learning disabilities. Group membership was a mixture of statutory and voluntary organisations and the private sector. The forums met four times a year with independent Chairs, these chairs had membership on Locality Community Care Planning groups acting as community representatives.

These mechanisms had produced tangible results, which had moved beyond information sharing such as developing studies and surveys, organising meetings, establishing a youth club as well as consultation and information distribution. There was also a countywide users network, providing support and training for local user groups, again linked to the seven forums. There was also a carers support network in the county, this was carer-led and involved the development and support of carer groups. The network also reflected tangible results such as training provision, development of a young carers project, advocacy of carers' rights and the identification of service gaps. The area also reflected a number of community programmes, partnership projects that supported community development, this included seven healthy communities projects as well as borough-based Crime and Disorder Groups. However, a Health Authority document in June 1999 had highlighted the lack of strategic planning and decision-making in relation to such partnership development.

7.8 The Public Involvement Strategy

The provenance of the public involvement strategy came from a draft document 'Framework for Public Involvement and Consultation for PCGs' produced by the health authority in May 1999. This was developed with the aid of a subgroup, with a membership of 21. This included lay members from 7 local PCGs, various statutory and voluntary representatives as well as the Health Authority Lead for Public Involvement (a Chief Executive for a local PCG). The aim of the framework was to

direct and support PCGs and to identify the existing groups and forums available to help them develop public and community networks, a potentially effective strategy identified within associated literature (see Taylor 1995, Barker et al 1999). However, throughout the document there was a strong emphasis on the limitations for public involvement, in places this was linked to the operational level of the PCG.

'PCGs at level 1 & 2 operate as subcommittees to the Health Authority. The Health Authority taking the lead role in Statutory Consultation and Strategic involvement of the public, users, carers, and partners'.

The document suggested the level of involvement and accountability that would realistically be expected of PCGs and identified performance indicators to measure progress, an important element in planning initiatives (Beresford and Croft 1993). This was reflected in the documents goals for year 1 & 2 in relation to public involvement and also highlighted continuing health authority control. The document provided little detail regarding training, funding or resources, however it did identify four models of involvement suggested by the NHS Executive Quality and Consumer Branch, the Institute for Health Service Managers and the NHS Confederation (see Appendix One): -

- Direct participation of users
- Informed views of citizens
- Community development
- Local scrutiny and accountability

Realistic performance indicators in relation to these four models were established within the document. The PCG public involvement strategy reflected the work within the above document (see Appendix 20) and continued loosely to follow the four models. The strategy contained seven modules: -

- PCG Board Meetings in Public
- Direct Involvement of User and Carers in the planning and evaluating of services
- Clinical Governance working with patients to improve the quality of service and gain better understanding of their needs
- Profile mapping of PCG area
- Community involvement in Health Improvement Programme

- Communication with stakeholders
- Corporate governance
- Support work of the Health Authority and other agencies

Interestingly, the work on a public involvement strategy had started in May 1999 and although some of the areas on the strategy were on going, there seemed an inappropriately long time delay between May 1999 and April 2000 to have a visible and available strategy. Limited support staff may have been a contributing factor, research by Wilkin and Shaeff identified that most PCGs (n=72) had not appointed key staff before April 1999. However, as can be seen from Appendix 20 - all areas gave details, timescales, with allocated responsibility for actions and as well as performance indicators, reflecting a strong focus on information giving. Through analysis of the draft strategy the following areas became the main focus of the research: -

- Profiling Exercise
- Public Participation Subgroup
- Open Day
- Health Improvement Initiatives
- PCT Consultation

The draft strategy was presented at Board meetings in February and April 2000 and was developed by the lay member and communications manager. Discussion at the public Board meeting in February 2000 also suggested the responsibility for the strategy was left with them and not shared, its vision focusing on service planning.

'The intention is for public involvement to be interlinked and ongoing in the work of the PCG, and not as a series of stand-alone one-off consultations. There will be a variety of ways to consult and involve people in the decision-making around service planning and future priorities' (Public Involvement Strategy 1999-2000).

The production of a strategy was acknowledged in the PCGs Annual Report (1999 – 2000) and was reviewed annually via the Public Participation Subgroup with progress reports were given at public Board meetings (February 2001).

Importantly, both lay member and communications manager showed a good awareness of the integrated nature of involvement and the need for the parallel development of a communications strategy (NHS Executive/IHSM & NHS Confederation 1998).

'This public participation strategy needs to be part of an integrated communication strategy where implications and outcomes are communicated to all appropriate audiences connected with the PCG'.

7.9 Public Involvement Initiatives

Profiling Exercise

PCG Board members (Chief Executive, Social Services Representative, Lay member and GP Board member) decided to initiate a mapping exercise over nine months (1999/2000), setting up meetings for different client groups. The meetings were planned to help the PCG and service providers learn about the range of services throughout the boroughs and identify service gaps. The decision not only recognised the importance of profiling (advocated by Barker et al 1999, DoH 1999a, NHS Executive Northern & Yorkshire Region 1999) but also reflected the organisation's willingness to utilise existing groups and forums (Barker et al 1999).

Membership included 7 PCG representatives and 101 non-PCG participants. There were 8 working groups, which reflected the established local forums – physically disabled, carers, children with disabilities, children and families, elderly, mental health, learning disabilities, young people. Attendance ranged from 5 to 22, averaging 11 per meeting. However, further analysis of the document suggested difficulties with adequate representation and an over reliance on client and disease specific groups. Membership of the profiling group was developed utilising personal knowledge and established social networks, described in the document: -

'...selection of invitees depended to a large extent to those known to PCG Board and staff members' (Profile Locality document)

There were some re-occurring members, the CHC member was involved in two groups, a further 6 participants were regular members of public participation

subgroup, perhaps suggesting the need to develop different mechanisms to increase and widen such involvement. Discussions with PCG staff revealed a limited knowledge of the wider voluntary sector and therefore this was not a comprehensive mapping exercise. No attention had been given to ethnic minority groups specifically, although forming 2.8% of PCG population, or groups experiencing access difficulties or suffering social exclusion. There was also great variation between groups, high numbers of members for elderly, carers and mental health working groups, but little or no representation for people with learning disabilities and children's services.

Groups were directed to a basic health agenda developed by the PCG staff, which included: - services, access to services, organisational/co-ordination, information, culture and attitude. Group members were able to identify: -

- Shortages in respite care, homecare, day care and housing
- Future health and service needs (pro-active general medical services and improved waiting times)
- Transport problems
- Organisational issues requiring greater service flexibility and training
- Equity of funding & the need to pool budgets
- Integration, communication and consistency in services
- Flexible & convenient services
- The need to be respected and valued as individuals

Although some of these issues had already been identified in a health authority document in 1999.

The meetings culminated in the development of the Profile Locality document, which was launched by the Chief Executive in September 2000. The document provided details of borough-wide statutory and voluntary services in a user-friendly matrix, as well as identifying key needs across client groups – participants were given one month for feedback. The Chief Executive (1) felt that the exercise and document had simplified communication networks and simple organisational issues had already been addressed. The main aim of the document was to use the data when commissioning and developing services. However, discussion with the Communications Manager in 2001, identified problems with ownership in treating the

profile as a developing resource. Further discussion with the Chair (2) of the PCG in October 2001, suggested that they still used this document but it was not formally evaluated. The PCG did not keep lists of whom it was sent out to and had given no feedback to participants regarding how the document had been utilised.

Open Day

An Open Day was held in May 2000, which was a two-hour event and advertised as an invitation by PCG Board members and staff to 'meet and share ideas with colleagues'. The event was held in the boardroom of the PCG headquarters and incorporated a number of displays highlighting the first year's achievements of the PCG. Interestingly, the public participation subgroup had not been asked to present a display, but the lay member had insisted. It became clear, that the definition of 'open' did not include members of the public. As with the training day (see Section 7.10), there was evidence of the influence of pharmaceutical companies, representatives were given areas to display drug products and they provided refreshments, their presence was defended by the communications manager as there was no budget to run the event. There was no evaluation of this event.

Public Partnership Subgroup

The first meeting of the subgroup was held in November 1999 and throughout the case study the subgroup maintained contact with the seven community forums, which included some shared membership and the lay member receiving the minutes of forums meetings. All meetings were held at PCG headquarters with all rooms on the ground floor, providing disabled access and were fit for purpose.

Group membership averaged eight members, with a majority of regular attendees – lay member, communications manager, two representatives from umbrella voluntary organisations, social services community services representative and a CHC member. Other attendees incorporated – citizen advice bureau, practice development advisor, voluntary project workers, Heath Authority representatives, management trainees, community development co-ordinators, borough council and elected representatives, which reflected an open and drop in policy and obviously related to topics within the groups' agenda. Following the first meeting, no PCG Board members attended subsequent meetings; such meetings on average were held every two months.

Agenda items were analysed from 9 meetings (from November 1999 to October 2001) with 44 items identified (see Appendix 21 – Agenda Examples). The agenda analysis reflects a variety of different types of work: –

- Strategic development (public involvement, ethics, communications)
- Information production (PCG leaflet, glossary, newsletter)
- Information review (guidelines for complaints, hospital treatment, locality meeting report, carers; strategy)
- Group development (patient participation group pilot)
- Information sharing (PCT development, PALS)
- Scrutiny (jargon, accessibility)

It also reflects the influence of the public involvement strategy on the work of the subgroup (see Appendix 20). Similarly the minutes were analysed - from the very beginning the minutes identified the agenda items requiring action and had written designated personnel responsible for each action. The minutes showed willingness for members to be involved in information gathering. However it also reflected the majority of the workload related to two members – the Communications Manager and Lay member. The positive view of the group is perhaps reflected in the CHC representative's comment: 'I thought that it may have been a rather ineffectual talking shop, however I think it has become more effective as it has gone along'.

Money became available, from the local health authority, for funding elderly projects in late 1999 and the organisation of bids were allocated to the lay member and communications manager and the issue was raised within the Public Participation Subgroup in January 2000. Again existing community networks were utilised, with lay member requesting a lists of needs from the elderly forum. With schemes evolving, the communications manager had designed a basic evaluation and monitoring form for discussion. Assessing areas such client group, number benefiting from the scheme, was the scheme in line with the bid proposal and current strategies and plans.

At a meeting in March 2000, with 7 out of 8 regular attendees of the Public Participation Subgroup, the lay member identified that the Joint Consultative Council (JCC) had accepted the PCG recommendations for Elderly bids and the PCG had been

praised for its process and applications. However, in analysing bids, there was a potential for a conflict of interest as members of the public participation subgroup were also actively involved in elderly projects. The CHC member wanted to maintain this funding facility within the new PCT structure, however a discussion with the lay member in October 2001, found this scheme halted. This function had been resumed by the health authority, with projects now being linked to NSF joint assessments, the lay member was disappointed by this and suggested a vagueness on how the funding would now be operationalised.

Health Improvement Initiatives

As with Case Study A, the PCG developed a number of health improvement events linked to the national HimP priorities, these included an exhibition to launch the HimP, Youth Project (Sexual Health) and Health Initiative (Older Adult). Due to communication difficulties I was not invited to part of these initiatives and, therefore, relied on secondary data through interviews and documentary analysis to describe and assess the events (see Section 5.10 for further discussion).

1. Exhibition

The launch was held in a local shopping centre in February 2000, with an approximated 200 contacts with members of the public and included a display with health workers offering basic health checks. In discussing the launch with the nurse representative, to her knowledge there were no written objectives for the launch and no formal evaluation. However, objectives were discussed in the HimP working group and the exhibition was to highlight the work of the PCG, falls in the elderly, exercise on prescription and to try an increase public awareness.

> Nurse Representative: '… you can't involve the public if they're not aware that you actually exist…'

The nurse representative, involved in blood pressure monitoring through the day, thought this practical and visual approach was effective with the public, highlighting that the stand was 'something to do with health' rather than just advertising something. Leaflets designed by the Communications Manager regarding PCGs were distributed, the nurse representative thought they were of a good quality although aware that they were not professionally designed and produced.

2. Youth Project – Teenage Sexual Health

The youth service working with the PCG, social services and health authority developed a project involving young people in decision-making for services that they required. A sexual health questionnaire was developed and distributed to all youth centres within the one of the boroughs to establish client views on sexual health services. A parallel survey had taken place within the other borough that was located within the PCG area. With a view to replicate, the nurse representative had liaised with a borough colleague in its development. The survey involved utilising community youth workers to help access sites as the nurse representative noted it was about '…finding the right person who can get to the public, and the right public that you want to hit, rather than just anybody…' - youth workers were identified by established networks including antenatal clinics, social workers and the health visitor service. The questionnaire was being analysed in October 2001, via the Clinical Audit Department.

3. Health Initiative (Older Adult)

A health promotion event was held in September 2001, focusing on the Older Adult, with particular emphasis on promoting independence and healthy living and the venue was a private health club. PCG staff played a facilitative role, co-ordinating a networking event and targeted representatives from private companies, police, education, Age Concern, representatives from the University of the Third Age and voluntary organisations. The event included exhibition stands, a brief presentation by the nurse representative, with the main focus on group networking and lasted two and half hours. An Operations Manager planned the event, discussions (October 2001) revealed that this was the first public involvement initiative that she had been involved in and she had no training in this area. The event was described as a 'one off' and was for information exchange purposes only, consequently there were no specific objectives and no evaluation. The Operations Manager found the lay member very supportive and she was surprised at the level of skill and expertise within the community – both the health club and pharmaceutical company were involved with sponsorship.

4. Patient Participation Group

The lay member was involved in supporting a local patient participation group in January 2001. Again, I had to rely on secondary data collection, through interviews with the lay member, as I was asked not to attend the patient participation group meetings. The practice had sent out 150 letters to potential patient members, however only 4 had attended the first meeting. Over the period of the study, the patient participation group did maintain a membership of 7 members, with joint leaders and called itself 'friends of the practice', again, the group was GP instigated. Progress on initiatives was described as slow, on leaving the field area, the group was looking at developing questionnaires and practice leaflets, and whether a patient should be involved with practice meetings. There remained continuing issues surrounding funding, particularly who was going to pay staff to go to meetings? Although this was the lay member's first experience of setting up such a group, she acted as a support, giving information about the activities of other groups. She also acted as a PCG representative, dealing with complaints regarding the removal of a specific service. She was able to offer advice that the service would be re-instated equitably across the PCG area

7.10 Training

Board members took part in a half-day workshop in February 2000 entitled 'Engaging the public – Pinpoint Workshop'. This workshop was provided by a pharmaceutical company, one of a number of involvements noted within this case study. The suggestion was that the workshop 'will encourage you to think as widely as possible about your PCG and communications' – the workshop was arranged by the lay member and communications manager, however they saw it as a way 'to identify the corporate objectives for the PCG when working outside the boundaries of the NHS and in the public domain'.

18 PCG Board and staff members attended the workshop this included the lay member, chair, chief executive, communications manager, social service representative and nurse representatives. The workshop was customer focused and the participants were asked to scale customer understanding of the structure and function of the PCG. In relation to external customers, there was complete agreement that the level of understanding was very low indeed and the point was made 'do external

groups need to know'. In identifying who needed to be communicated with, the list was prioritised as: -

- PCG staff members
- Public (defined as patients, carers, non-users, local council).
- Policymakers
- Community Trusts
- Educators
- Media

(Borough councils, voluntary organisations, acute Trusts received no votes). Subjects that needed communicated related to PCG developments and PCG aims and objectives.

In the summer (2000), Board members took part in a three-day away training session, this focused on teambuilding with members giving presentations regarding their views on PCG development. The lay member took this as an opportunity to highlight issues with the ownership and prioritisation of public involvement. At this time she felt that the Board could be more supportive and proactive in relation to involvement initiatives.

7.11 PCT Consultation

In May 2000, the PCG declared an interest in PCT status for April 2002 and this would also include a merger with another local PCG. An outline plan of PCT status was produced by the end of the first year and a steering group was established, which included Board members from both PCGs (2 Chairs, 2 Chief Executives, 2 GPs, a Trust representative, Health Authority representative). Again, as with the Open Day, the lay member had to insist on being part of this group and would not have been asked otherwise. Part of PCT planning was the integration of primary and community care professionals in an organisational structure within the four geographical localities. Public consultation for PCT took place between June and August 2001, with a leaflet published in June 2001 giving information regarding the functions of PCG/PCTs and the implications of a move to trust status. Public access to documentation was also available on website, in the local library and from the Health Authority and PCG offices, comments could be made via E-mail, fax or in writing. A

summary leaflet was targeted at public places, voluntary organisations and waiting areas.

1. Public Meetings

There were three public meetings regarding PCT consultation, one held in the afternoon and two in the evening and I attended the two evening sessions. Both meetings were recorded and chaired by a CHC member, the PCG panel comprised of the Chief Executive, Chair and social services representative – the lay member was not asked to be a panellist. The meetings reflected low levels of attendance (n=24, in both sessions). Attendees were predominantly white and included CHC representation, lay members, local charity representatives, representatives from carers network, county councillors, forum representatives as well as health service managers and health professionals.

The meetings compromised of a laptop presentation, which gave information regarding the merger of the two PCGs and the proposed service provision and commissioning of the new PCT. The PCT organisational structure was also identified and the importance of developing partnerships with the local community was highlighted. An hour was dedicated to public discussion, which identified a number of topic areas. Within both meetings funding issues were prominent, particularly the transitional costs of the merger and the move to trust status. Concerns were highlighted about the future of specific existing services as well as the role of the community pharmacist and the private sector. There was little discussion regarding public involvement within the new PCT, although the importance of the local forums was discussed as well as concerns regarding the independence of PALS.

2. Consultation Document

The document contents included: -

- Introduction (Level 4 PCT)
- Why become a PCT
- Local Context
- Services to be provided and commissioned
- How we have responded to the needs of our community

Public involvement was discussed on pages 16 to 17, however there was no distinction made between the public and patient involvement, with a strong focus on care and treatment, service provision and planning new services. Again partnerships with local councils, social services, education authorities, voluntary organisations, community forums and the CHC were championed. The PCT Strategy placed the responsibility on the lead person of each locality to ensure that public involvement underpinned decision-making and action. PCG initiatives such as the Profiling Report and sexual health questionnaire for teenagers were identified, but no impact statements. The new structure PALS was identified but there was no discussion on Patient Forums. There was wide distribution of consultation document, with availability in a number of forms.

7.12 The Role of the Lay Member

The lay member presented as a highly experienced individual with a professional background in nursing. Her motivation to apply focused on a continuing interest in the health service, as she had been involved in user representation for over 30 years. This included membership of the Community Health Council, holding the national Chairmanship at one point, again, reflecting lay experience identifies by Brotchie and Wann (1993) and Davies (2001). Voluntary work was extensive, including advocacy, assisted access and ethic committees. In conjunction with her PCG work, she was Chair of three local charities with experience of public involvement initiatives focusing on public meetings, national and local debates involving the CHC. In early discussion, regarding her relationship with other Board members, she acknowledged the importance of her experience, which 'backed up comments on any health issue' and she also identified 'I feel accepted, feel valued, an equal member of the Board, made welcome'.

Training included a one-day session specifically focusing on the role of lay member, facilitated by the local health authority. Interestingly, the health authority also attempted a joint training session with social service representatives (PCG Board members), only two members turned up and the session was cancelled. However, there was a written job description evident with the health authority document 'Framework for Public Involvement', which focused on five specific areas.

The lay member would: -

- Contribute to a public involvement framework,
- Ensure public views/concerns were addressed by the PCG,
- Participate in a team approach to involvement,
- Ensure PCG accountability and probity
- Contribute to developing relationships with the local community, statutory and non-statutory organisations.

This document also recognised potential isolation and encouraged peer support, through membership of a health authority subgroup on public involvement. In discussing her own role perceptions, the lay member thought comments should come from a patient's viewpoint and she should act as a watchdog, monitoring involvement. She did not feel that she was a public representative '…the public didn't vote me into the position'. The view was one of an individual with specific experiences and that the lay member's expertise should be acknowledged.

The lay member presented a very different leadership style to that of Case Study A, with greater emphasis on direct personal action rather than facilitation. This is evident in the range of PCG activities, in which she led, supporting a patient participation carer group, joint development of the public involvement strategy, involvement in the carers strategy and the development of an ethics register. As identified within the analysis of the public participation subgroup, her workload far exceeded the allocated 2.5 days per month. As reflected within the national survey, she was involved in a number of subgroups, which included community care, commissioning and health improvement, however in discussion she would have liked greater input into clinical governance. She was also a panel member of a Referral Advisory Panel and acted as a PCG representative on a number of occasions. Discussions in October 2001 identified her intention to apply for a non-executive directorship with the PCT (see Appendix 22 for detailed discussion on role development).

However, her experiences also highlighted frustrations. Discussions in early 2000 identified a perceived lack of Board support in relation to public involvement. She developed a number of strategies to address this issue, starting with rotating her membership of subgroups, taking the opportunity to advocate public involvement in all areas as well as utilising a three day training workshop, again to advocate the

public involvement strategy. Discussions with the Communications Manager in January 2001, identified the remaining perception that the lay member was a ''one-man band' - groups without lay member input were still struggling with the concept of public involvement.

7.13 Case Study B Evaluation - Perspectives on Public Involvement

This case study strongly reflected aspects of Meads (1999) 'defence association' and 'executive agency' PCG models. Meads (1999) describes a defence association as the most likely form of PCG organisational development, representing an exact configuration with past professional traditions in primary care and the conventional role of GPs in local social and political systems. An executive agency thinks tactically rather than strategically, often a product of GP conservatism, characterised by a small number of professionals and managers with developed negotiating and contractual expertise (Meads 1999). The agency can develop out of a defence association, reflecting an internally defined change agenda, lacking the maturity to move forward strategically on health issues (Meads 1999). Case Study B, as an organisation, reflected a restrained and protective stance operationally, with a very cautious approach regarding its involvement with the public. Interviews and documentary analysis suggested a number of issues relating to this approach: - budgetary deficit, perception of citizen capacity and organisational incapacity, all impacted on the methods of involvement and the public involvement strategy.

Budget Deficit and Health Economy

Health authority literature openly discussed financial pressures, annual spending on NHS services needed to be reduced by £10 million pounds over two years, forcing a review of the delivery and availability of local services. Within the PCG, there was a strong focus on local health economics, the Annual Report (1999-2000) identified overspend of £186,000 on the prescribing budget. This initiated the introduction of a prescribing formulary in practices. There was a also a strong emphasis in preventing money from moving out of the local primary care economy, this included purchasing beds in nursing homes to prevent unnecessary admissions and the development of the Referral Advisory Panel, an attempt to reduce out of area referrals. The deficit impacted on other areas of healthcare spending and this included public involvement. Discussions with the Chief Executive (1) in May 2000 identified the frustrations in relation to this situation, with the health authority blocking initiatives. Funding streams were linked to disease and illness not health and prevention; she noted that this had had a de-motivating effect on staff. The effects of the situation can be seen in this extract from the Primary Care Plan (April 2000:21)

'Closer links and structures with social services and borough councils will be developed, working in partnership with local people and professionals to take ownership of the local health economy'

Lack of funding left the lay member and communications manager trying to find financial support for public involvement initiatives, with pharmaceutical companies supporting Open Events and providing training sessions. However, the quality of training was extremely questionable and focused on communication rather than involvement.

Perception of Citizen Capacity

A mixture of past experiences of public involvement, a precise view of public credentials and media training had impacted significantly on Board members' perceptions of the publics' ability to participate in decision-making. A previous experience with public involvement in the attempted closure of a local casualty department had affected some professional perceptions. The GP Chair (1) was angry over the media coverage of the closure and was 'disgusted' with a minority of people that had caused problems.

'…user groups have a point of view, that's why they're useful but they are not in a position to make relatively detached choices, which is what health administration needs to be about …

Media training had a negative impact on developing relationships with the media. The media was portrayed as manipulative rather than acting as a focus for public participation or information. Particular credentials were linked to the type of citizen that should be involved, which related to being competent and informed (see Harrison and Mort 1998) and their recommendations should be reasonable and sensible.

'…someone who is intelligent enough and committed enough to put the time in, to allow them to come up to the level of knowledge about process and situation, that allows them to make an involved contribution' (GP Chair (1)).

'…people need to understand the primary care systems…' (Lay member)

Discussions with Board members and PCG staff revealed a continuing belief that the majority of people did not wished to be involved in decision-making, an area that was also identified in Phase Three interviews (see Section 8.1.9).

'…the public as a whole do not want to get involved very much, I feel they liked to be informed …(Communications Manager, 2000).

Exceptions are linked to circumstances, which affect the public personally or people who harbour vested interests or hidden agendas.

'I think its very hard having public involvement within the PCG because the people who want to be involved sometimes have a vested interest to why they want to be involved …' (Nurse representative)

'…the public don't want to be too involved, they become involved and want to be involved when something happens to them or their family…' (Lay member)

'…there are a, often a small vocal minority who, who represent their views and when I was at the CHC, I stayed on, one of my aims was to establish some sort of erm link, a group that maybe represented the population rather than the , this smaller minority …' (Chief Executive (2)).

There were concerns that the public perspective could be distorted and that public involvement needed to be carefully managed. This tentative approach could explain the limited involvement of the public within this PCG, with restrictive external communication and a strong emphasis on current service users.

Strategic Development & Vision

As with Case Study A, there was a written public involvement strategy developed by the lay member and communications manager. The strategy benefited from using an explicit framework in directing objectives, such objectives were realistic but simplistic, with perhaps too strong emphasis on communication and access. Again although board approved, it was not a collaborative process and the strategy

developed separately to other board and workgroup activities. As a consequence there were constant ownership issues throughout the duration of the study.

It was clear that there was an over reliance on the lay member and communications manager to develop and manage initiatives. The public participation subgroup agenda certainly reflected the strategy's objectives and areas such as profiling and accessible public meetings were realised. It also caused the lay member to develop a personal strategy of circulating workgroups to advocate public involvement. However, discussions and documentary analysis suggested that, implicitly, for many board members this focused on informing the public on why decisions were made. Although the strategy reflected the use of performance indicators, evaluation took the form updates at board level.

Communications Policy

The communications policy had received little attention, accountability issues relating to accessible information e.g., glossaries, document availability had been addressed, although, important issues relating to public awareness and wider network development were not (see Kelson 1997, Entwistle et al 1998). Both the lay member and communications manager identified a lack of planning regarding lines of communication, furthermore, communication objectives identified in February 2000, mostly remained unrealised. There was no attempt at wide distribution of the PCG leaflet, with increased circulation being blocked at board level. Website development was also slow and although it was due to be ready in April 2000 it was still not available by October 2001. Opportunities to share information with the public, such as the Open Day and newsletter, were specifically targeted at PCG staff and the health service community.

It was, therefore, of little surprise that poor public awareness of the organisation was acknowledged 'I would guess the vast majority of people know very little' (Communications Manager). However, this was not always seen as problematic, there were concerns over organisational capacity (Christie 2000), too much attention, the Communications Manager suggested, could divert attention, with limited staff and expertise in place to deal with this public interface. However, the social services representative worried about the consequences of low public awareness as the PCG

moved to trust status, would people think that they been operating 'behind closed doors'.

Methods of Involvement

- Profiling Workshops
- Exhibition
- Health Initiative Day
- Patient Participation Group
- Sexual Health Questionnaire
- Open Day
- Public Participation Subgroup
- Re-development of public Board meetings

Again, an evaluation of above methods tends to suggest that they were not particularly wide ranging, with a strong emphasis on information exchange. As discussed earlier, the PCG made good use of existing structures and an established network of forums, aided by the Social Services representative, who had been actively involved with the development of this network. Similarly, the nurse representative utilised established community projects, accessing a youth worker and youth centres for distribution of a sexual health questionnaire. However, the forums reflected a potentially restrictive set of care/disease-focused groups, limiting involvement to current service users and carers. These groups were accessible (Taylor 1995, Chambers 2000) but could be seen as part of an exclusive practice (Brownill and McInvoy 2000). Discussions with Board members and PCG staff identified the need to widen public involvement further, this included developing a network of communications with the local community and the need '…to get out to the people…' although this had not been realised.

Limited Practice Development

Only one patient participation group was operationalised out of 22 practices within the lifespan of the research study, although all practices were audited, little material related to patient or public involvement. The PCG developed four posts known as Practice Development Advisors and associated personnel began working for the organisation in September 1999. Their remit covered a wide variety of areas e.g.,

information technology; organisational and staff development; NSF implementation; clinical governance; risk assessment; audit as well as Professional Development Programmes and Personal Learning Programmes. Again, this was an opportunity to incorporate public involvement that was not realised and none of the advisors had expertise within this area. Clinical Governance recommendations focused strongly on information gathering, suggesting that practices should have an effective method of recording complaints, compliments and a means of taking appropriate action, although it was not clear what mechanism would be in place to deal with such issues.

Low Prioritisation

A number of essential factors seemed to be missing within the PCG's organisation, suggesting that public involvement was not perceived as a priority or, at times, a need. The views of the health authority were immediately limiting, there was also a lack of Board membership on the public participation subgroup and the workload of the lay member suggested a lack of corporate responsibility '…they don't perceive the need yet, once we present it to them they probably will …' (Communications Manager). Discussions with the social services representative suggested focus had been on prescribing, clinical governance and then PCT status.

'… it is discussions on PCT that we are beginning to think about how we go out to the public, we are now focusing on the softer bits', (Social Service Representative)

She described this process as time consuming and there was a feeling of being outnumbered, highlighting difficulties with the GP majority. An interview with Communications Manager in January 2001 identified continuing problems with ownership and a great fear of 'floodgate demands' and there was still a problem with protectionism. There were discussions of a lack of corporate vision with GP focusing on their own practice constituents. The social services representative also identified this difficulty, suggesting that it needed to be challenged but in a non-threatening way.

Personnel/Expertise & Training

The need for training relating to public involvement was recognised as important by the Chief Executive (1), particularly in changing professional viewpoints, however

actual training was minimal. Discussions with Board members and PCG staff suggest that available literature, recent research and evaluative tools had not been utilised, although, the manual by Barker et al (1999) was highlighted by the communications manager and lay member. At times in-house experience was under-utilised, for example, the social services representative had previous experience of community care planning, stakeholder conferences, public meetings and user groups. However, the PCG had developed a Service Level Agreement with two borough voluntary umbrella organisations, enabling representation and participation in PCG operations and they were members of the public participation subgroup. The Communications manager, as with the partnership development manager in Case Study A, had multiple roles. She described a large administrative role, which '... defeats what I am doing' and there were difficulties with the lack of adequate support staff. The lack of a discrete position, translated into an over reliance on the lay member, although highly experienced following work with CHC, charities and nursing, she recognised that she had limited experience of public involvement methods, literature and research. Overall there seemed a strong reliance on previous experience rather than training or expertise.

Achievements & Difficulties

Chief Executive (1) maintained that the PCG had 'turned a corner' in valuing the lay perspective, noting 'When I compare attitudes and thoughts to some other PCGs attitude I think we're a lot better'. She acknowledged the role of the lay member for re-imposing the importance of involvement continually, however recognised that the Board could have been more supportive in relation to her objectives. The lay member had recognised a cultural shift and a refocusing on partnership, but was realistic about the pace change and the GP Chair (2) also recognised the importance of having an active lay member. Discussion with the CHC representative identified the PCG as 'remarkably open' and he highlighted the importance of using the local forums as an information source and also recognised the contribution made by the communications manager and lay member.

A dedicated member of staff had been employed in September 2001 and was setting up an implementation project group with the development manager and practice manager. The main challenges were seen as disseminating public involvement

principles beyond Board level, finding funding, developing action plans to meet objectives and formal evaluation techniques. However, as with Case Study A, evaluation of public involvement initiatives proved informal and inadequate through the period of research. Other problems related to practice management; discussions with the Chief Executive (1) highlighted the resistance of GPs to any form of imposed management system and she was having to deal with a number of problematic practices. The GP Chair (2) identified difficulties in finding members of the public as opposed to user representatives or organisations, noting that: -

'… the number of service users who actually want to be involved is quite small and what you tend to find is that those people who are prepared to get involved get over stretched …'

7.14 Comparative Summary

Both involvement strategies were developed by the lay member with limited evidence of collaboration, both appearing in final draft form around April 2000 and presented at Board meetings. Although very different PCG areas, many public involvement initiatives were paralleled, with a strong emphasis on the national HimP priorities e.g., Open Day/Stakeholder Day (main focus informing staff), sexual health questionnaires (using existing networks for distribution), Healthy Heart Day and Exhibition (both involving health checks, similar number of attendees n=200), Older Adult public events, the majority influenced by the national health agenda. As with many PCGs nationally both case studies had co-opted CHC representatives on to the governing board (see Alborz et al 2002). However, visible impact of involvement and associated recommendations were unclear, Anderson and Florin (2002:30) also identify this difficulty 'An event is run, views are recorded, a report goes to the board, but it fails to impress'.

Both had developed subgroups to help facilitate public involvement in their organisations. Although their roles developed quite differently, both lay members had felt a valued member of the PCG team and made substantial contributions (also highlighted in Bond et al (2001)). Profiles reflected highly experienced and knowledgeable individuals in relation to the health and voluntary sector. It is clear that the work of the lay members proved invaluable in promoting public involvement

and both described their experience as positive and rewarding. As with other PCG case studies (see Bond et al 2001, South 2004) a lack of training was identified, with personnel heavily dependent on experience. Long standing theoretical literature (Mullen 1999) was under utilised with limited dedicated staff to take public involvement forward.

Case Study A, reflected an enthusiastic and supportive approach to the philosophy of involvement, with a greater number of Board members and staff actively involved in this area. Case Study B; projected a very cautious and protective approach, with a stronger emphasis on current service users, carers and the local health economy. It was clear that there was more funding and greater organisational capacity to support involvement initiatives in Case Study A, such initiatives tended to be on a much larger scale. However, perhaps because of such financial limitations, Case Study B was much more successful in utilising existing involvement structures. Equally, the public participation subgroup was able to be more effective as a group by closely aligning itself to a more realistic, if simplistic, public involvement strategy.

Both PCG areas experienced difficulties in widening participation, particularly the general public and hard to reach groups, and missed opportunities for extensive practice development. Case Study A developed a predominant community development approach, Case Study B; reflected a more eclectic approach, through the use of established public involvement models, however, failed in its implementation, with too strong an emphasis on information exchange and user involvement. Interestingly, Pickin et al (2002:34) also identify many of the areas discussed within this chapter and Box 27, suggesting that ineffective strategic partnerships between lay communities and statutory organisations focus on five distinct areas: - community's capacity to engage, skills and competencies of organisational staff, dominant professional service culture, overall organisational ethos/culture and the dynamics of local and national political systems. The authors assert that understanding the relationship and power balance between communities and statutory organisations is crucial for effective involvement and this is discussed further in Chapters 9 & 10.

BOX 31

Comparative Summary

- A variety of public involvement methods observed – strong emphasis on consultation and information exchange
- Implementation of Initiative Recommendations weak
- Inadequate staff support and training in relation to public involvement
- Rapid organisational development – staff and locality changes
- Highly skilled and motivated lay members
- Long standing capacity issues for staff and lay representatives
- Variable levels of commitment to public involvement – operating on an individual/group level rather than organisational
- Lack of holistic definition of public involvement – strong emphasis on community development or user involvement
- Inadequate funds and resources for public involvement
- Non-collaborative strategic development in relation to public involvement
- Compromised communications strategy
- Lack of sustainable expertise in public involvement methods and initiatives
- Inadequate evaluation of initiatives – emphasis on progress reports
- Public involvement remained a lower priority

CHAPTER EIGHT

Interviews

Introduction

This chapter presents the data analysis from Phase Three of this research study, which focused on a series of telephone interviews with lay members identified through the national survey. This phase focused on three distinct groups of informants for data collection and analysis: -

- Lay members who had become the lead/chair for public involvement within their primary care group
- Lay members who had expressed particular negative aspects to their role
- Lay members who had gained non-executive directorships or chairs within PCTs

Lead/Chair for public involvement

Twenty lay members took part in a structured telephone interview incorporating an interview schedule (see Appendix Seven), which focused on four specific areas (see Section 8.1). Interviews were recorded; open questions within the interview schedule were transcribed and analysed utilising content analysis, factual content was analysed utilising SPSS (version 10.0).

Negative Experiences

Seven lay members were interviewed regarding their negative experiences as a board member within a primary care group. These were open-ended interviews, with issues highlighted within each lay members' questionnaire as the main areas for discussion. The interviews were transcribed and analysed using content analysis.

Non-executive directors and chairs

Thirteen non-executive directors and four chairs of PCT boards took part in a series of open-ended interviews, the first and third interviews were utilised within the data analysis of this research study and covered a time interval between April and October 2001. The data was analysed using content and discourse analysis. The results of the data analysis are presented with in these three distinct areas - Sections 8.1, 8.2 and 8.3

8.1 Lay Members Leading on Public Involvement

Informants were interviewed in April 2001, using an interview schedule incorporating the following four areas: -

Role Development: length of service, training needs, role definition, overall experience and leadership in public involvement

Public Involvement Strategy: The use of subcommittees, methods of involvement, evaluation, funding public involvement initiatives, salaried personnel related to involvement, successes and barriers related to public involvement

Primary Care Trust status: mergers, public consultation and lay member involvement, consultation methods

Previous experience and personal background: previous roles within CHC, non-executive positions and previous experience as chairs and knowledge of public involvement initiatives and disability status (see Box 32)

BOX 32

Personal Background of Lay Members leading Public Involvement

20% of respondents had had previous experience of lay membership
15% had been non-executive directors
65% had previous/ongoing experience in the voluntary sector
30% had been involved as members of community health councils
90% had previous experience of chairing
75% stated that they had public involvement experience.
However, the description of their level of knowledge of public involvement methods was mixed: -

Very good	15%
Fairly good	45%
None/poor	40%

Those members who identified a registered disability: -

No	90%
Yes	10%

8.1.1 Inadequate Training

The informants' length of service on PCG boards ranged from 18 months to over 2 years and 75% of informants (n=15) had been with the PCG as a shadow board. Only 50% (n=10) of informants had received training related to their role as lay member, again, supporting national survey findings that training provision was inadequate.

However, informants were able to identify a range of training areas that could have supported their role development: -

- The structure of the NHS
- NHS jargon
- General practice (structure and operation)
- Financial arrangements
- Public involvement training
- The role of the lay member
- Public relations
- Complaints procedure
- Communication and media skills
- IT training

Some of these areas relate to integrating into the NHS culture and also reflect training needs identified by Brotchie and Wann (1993) and Bradburn et al (1999), Appointments Commission (2005), however, informant discussion did not focus on challenging existing problems such as the use of jargon.

8.1.2 Role Construction

Lay members proved adept at their own role construction, which focused on four core elements: - offering a different perspective, networking, advocacy and public representation. A different perspective for some members meant bringing commonsense or objectivity to discussions and decision-making. It was also interpreted as being able to offer a non-professional view to board operations and offer as well different skills and experiences.

> LM529: Well I think one important thing I found was to try to, if you like, bring the specialist, er down to earth a little, er there were times when discussions got a bit esoteric and slightly off tack …

Some informants identified the ability to act as a conduit or vehicle for the exchange of information between the board and the community.

> LM332: … to try as best as I could to convey what was happening on the board, the decisions that had been made by the board to as many people as possible …

However, some of the difficulties relating to open dialogue is emphasised by this extract, particularly in relation to issues of confidentiality.

LM371: I suppose I would say er the conduit for erm public opinion into the PCG. but I think it was also erm it could have been a good conduit the other way but er there were some problems in that regard really, not least, I mean which is the confidentiality …'

Acting as an advocate for users and members of the public was also incorporated into role descriptions. In some cases, this took the form of persistently reminding board members of the public agenda.

LM523: To make sure the patient wasn't forgotten, erm amongst all the talk about how to do the job and last person that ever seemed to get mentioned was how this all was going effect the patients

In others, it was advocating the user involvement within the decision-making process.

LM574: … making sure that they're kept aware of what the public needs were and public input.'

In other circumstances it was the ability to act as an agent provocateur, in questioning the decisions made by the board. However, as this extract highlights lay members needed to balance such advocacy/questioning with need to be accepted as a team member.

LM416: … its very difficult because you can't helped be sucked into the group activity and you almost find yourself sometimes saying 'well of course we can't do that' and you think hang, hang on we are not suppose to be 'we' on this…

A role as a public representative proved to be a most contentious issue, a number highlighted their role as the public voice.

LM202: … erm representing the voice of erm the community on the board and erm keep the strong links with the local community and voluntary sector

However, the difficulties in attempting public representation were also emphasised

LM332: … I decided at the end of the day my role on the board was not to try and represent 185, 000 people …'

8.1.3 A Challenging Role

The lay member experience was often described as double-edged in most cases both being enjoyable but frustrating.

LM312: Frustrating in very many ways but having said that I obviously enjoyed some say in the decision-making process

Areas of frustration covered a number of different topics, these included problems with role expectation and the lack of guidance and understanding relating to public involvement.

LM529: … it was assumed that the lay member would look at the public engagement side of things, because it was a thing that the doctors and

nurse etc didn't really know anything about and properly didn't have time to anything about either…'

Other frustrations focused on limitations of time and the lack of tangible results.

LM523: Frustrating (Pause) I put a lot of work in erm sort of erm making preparation for doing allsorts of things and none of them have come to fruition. Some of that was because of erm of the various things that were going on in the PCG and the fact they were going for PCT status, which obviously took precedence …

However, experiences of lay membership were also linked to personal development, viewing the experience as stimulating.

LM574: I think I've learnt a lot more about strategy and the NHS, and that has been useful as an advice worker and as a user of services

8.1.4 Sporadic Strategic Development

Four of the lay members had volunteered for the lead in public involvement; the other 16 acknowledged that there had been an assumption by other board members that they would take on this role, which is summed up by this statement 'I think if I'd said no I think they would have fallen off their chairs!'. 70% of informants had been involved in developing the public involvement strategy, however, 7 out 20 lay members identified no tangible strategy at all.

LM481: … honestly I don't think there's really been, what you would say a public involvement strategy up to quite recently …

Those lay members who had been involved in developing a strategy, took a number of routes to develop the document. One of these was external involvement such as Community Health Councils, voluntary organisations as well as, in some cases, statutory organisations. Some lay members had sought internal involvement through the use of the public involvement subgroup, however, in some instances, it had been left solely to the lay member.

LM163: I wrote, wrote on my own, it went through the board …

Within this discussion, it became evident that the term public involvement strategy had been re-interpreted or re-defined, for example as a communications strategy, terms of reference, a set of objectives. Others identified the issue of strategy being a paper exercise, where documented objectives were not realised in practice.

LM416: … I was never able to get any of the practices to take on board issues like having a patient participation group or anything like

8.1.5 Dominance of Multi-Agency Subgroups

85% of informants had formed subgroups related to public involvement, again reflecting the results of the national survey and other research projects (see Wilkin and Shaeff 1999). The average membership was eight. The results suggest that such subgroups are multi-agency in characteristic rather than comprising of individual members of the public or community groups. 4 out of the 17 groups were board dominated, with board members out numbering external groups and organisations. 10 out of 17 were predominantly multi-agency in composition.

Table 12

Group Frequencies

CHC	12
CVS	10
Other PCG	8
Trust	7
HA	5
Social Services	5
Chief Executive	5
Nurses	4
LA rep	4
Others	4
GPs	3
Chair	3
Users group	2
Carers group	2
Local government	2
Councillors	2
Practice managers	2
Non-executive	1
Citizen Advice	1

As can be seen from Table 12, the most likely group memberships involve the Community Health Council, voluntary organisations as well as various sections of the health and social services. Members or groups who are less likely to be involved in such subgroups are general practitioners, chairs of PCGs, user and carer groups, local

government representatives, health authority non-executive directors and community groups. These groups, therefore, could not provide a comprehensive local perspective; furthermore, the lack of health professionals perhaps suggests other areas were a priority.

8.1.6 Consultative Methods & Limited Evaluation

The average number of methods utilised by the primary care groups studied was eight specific initiatives.

Public Involvement Methods

Table 13

Subgroups	17
Newsletter	17
Website	15
Co-opt member to board	14
Press	14
Exhibition	12
Survey	10
Local Forum	8
Health panel	7
PPG	7
Workshops	5
Conference	5
Community development	5
User group meetings	5
Public meeting	5
Others	5
Meetings with voluntary	4
Citizen Panel/Jury	3

(The category of 'others' included: - call cards, road shows, health promotion in supermarkets, access groups, finance for development of database, open days.)

In analysing the types of methods utilised by PCGs to involve the public, the data was re-categorised into the following areas: -

- Information Exchange
- Group Processes
- Meetings
- Community Development
- Forums and panels
- Conference and workshops (see Figure 7)

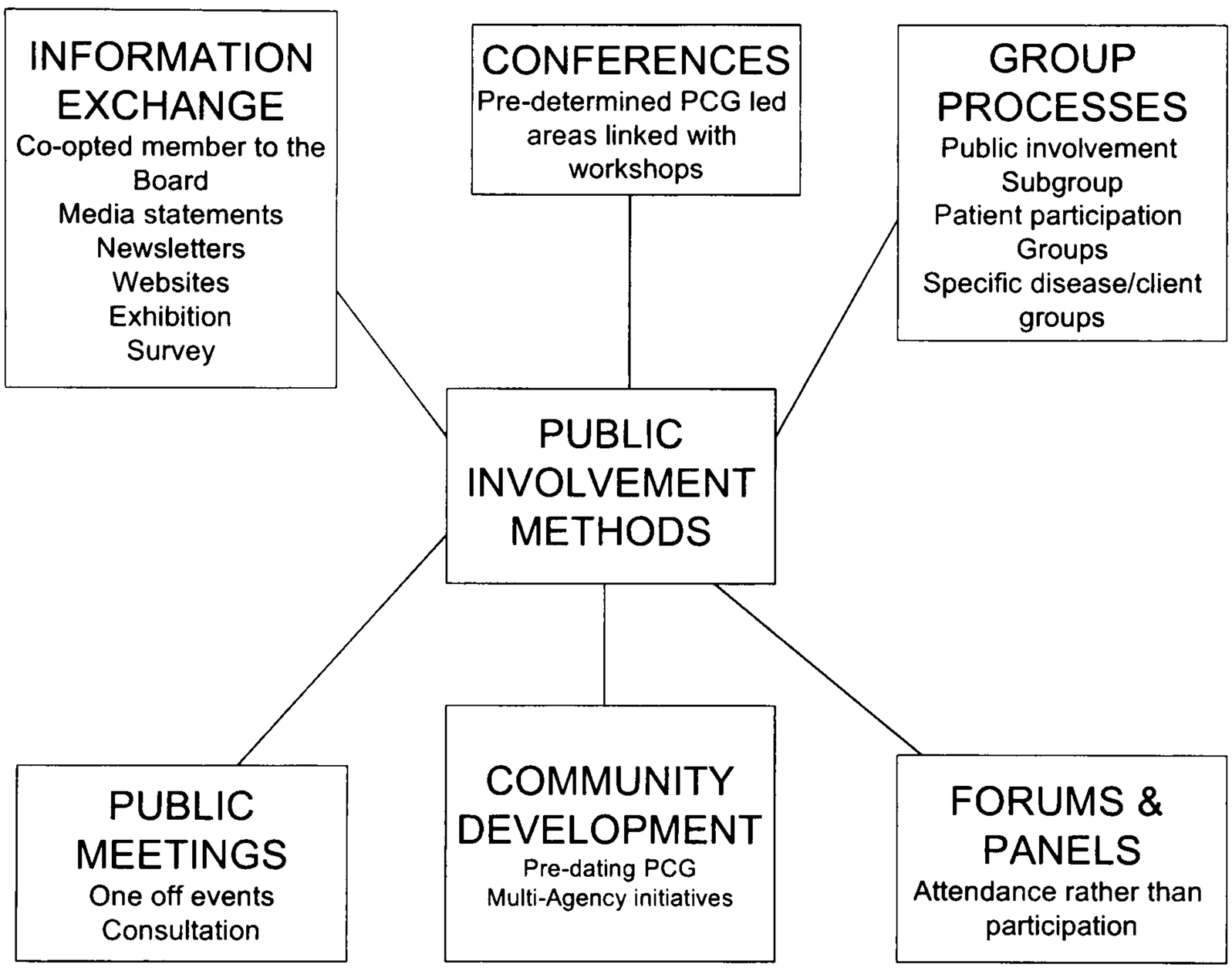

Figure 7: Identified Involvement Methods

The majority of public involvement initiatives were allocated to the information exchange category, such methods focused on the provision and/or the retrieval of information (also highlighted in research by Bond et al 2001, Pickard and Smith 2001) and, perhaps, supports assertions that there were few genuine examples of active participation (Crowley et al 2002). Many PCGs had co-opted members at board level, such members were predominantly members of the local CHC, however, this also included voluntary organisations. Such membership had only observational status rather than voting rights. The media was predominantly utilised to give statements or for the notification of forthcoming events, however, four lay members identified a

more active relationship, in discussing local health matters or to circulate primary care.

Newsletter distribution was variable, from just health services premises to a wider circulation incorporating community groups or door-to-door delivery. Many websites had been developed at health authority rather than PCG level and none of the lay members could describe the capacity of such websites, particularly in relation to their interactive ability. Exhibitions were characteristically one-off events focusing on a specific health-related issue, surveys again tended to focus on patient satisfaction or an evaluation of a specific service.

The most prevalent group related to public involvement, functioned as a subgroup of the PCG board. On the evidence from the study, subgroups are predominantly multi-agency, in a minority of cases having professional dominance. Some leads had identified the development of PPGs within the PCG. The majority had developed one or two such groups, however, one PCG had developed a network of PPGs, with nine operating in their area. Users groups were also identified that were involved within specific health-related groups e.g., coronary heart disease. Some lay members identified the use of public meetings further to the statutory requirements, again such meetings tended to deal with specific issues and were predominantly one-off events and suffered from variable levels of attendance. Less structured meetings were held with voluntary organisations, many examples focusing on PCT consultation.

Community development was under-utilised by many of the PCGs with only 5 out 20 members identifying this method. Such projects tended to predate the formation of the PCG and were multi-agency initiatives. A number of groups were identified within the forums and panels category, particularly health panels and community forums. This method of involvement was described in terms of lay member attendance and observation rather than active involvement. Conference and workshops predominantly focused on predetermined areas generated by the PCG, which were health related and were again one-off events, such tools were often linked together where workshops appeared within the structure of a conference.

Importantly, 90% of respondents said that the methods utilised to facilitate public involvement had not been formally evaluated. 10% had limited evaluation on single methods such as surveys, or had used attendance levels as an evaluation tool. This seemed very pertinent as when discussing the effectiveness of such methods some informants discussed their perceived lack of effectiveness.

LM162: I don't think we've touched the surface yet

Public apathy, in some cases, was linked to such ineffectiveness

LM163: It's difficult to say because the public are very fickle they are interested if it, if they feel its something connected with them, if its not, they feel connected with them, then they are not interested.

LM312: ... we didn't have any strategy for involving the public but we did try to hold meetings in different parts of the borough and the board meetings were open to the public and were advertised in the local (pause) but we really didn't get much response

Effectiveness, where highlighted, focused on establishing networks with local structures and the success of specific projects (i.e., walk-in clinics, information days)

LM416: Personal linking to organisations and availability. The Chair, chief executive and lay member went out to groups, bringing people into open meetings, asking people to come

LM202: Without doubt our links with the voluntary sector, I mean you're quite heavily involved with them, we've got a good CVS locally and good, good user groups ...

Some identified small group processes whilst two of the informants thought that the relationships with local health forum or panels were the most effective.

LM529: ... from the bottom-up, engage small groups at a time erm that can't be the end of it, I don't favour particularly the large-scale conference ...

LM523: Small groups where people felt free to say what they wanted to say and weren't intimidated ...

8.1.7 Inadequate Budgets & Issues of Capacity

75% of informants said there had been no specific budget for public involvement. The other 25% had some budget, however, this was not identified as ring fenced, rather a number of attempts to find money once initiatives had been identified, only one lay member identified a specific budget, which was £25,000. As with the case studies, capacity issues were identified, particularly, relating to dedicated personnel (see Anderson and Florin 2000b, Bond et al 2001). 9 out 20 of the informants stated that

there no one specifically employed by the PCG to facilitate public involvement. Of the 11 lay members who gave a positive answer to this question: -

- 5 of these named personnel had been recent appointments
- 3 of these named personnel had been seconded from other organisations such as the CHC/community trusts.
- 4 of these named personnel had other responsibilities within their job descriptions
- 2 of these named personnel were working on specific project areas
- Only one of these named personnel was identified as a senior management position

8.1.8 Perceived Lack of Success or Small Gains

Some lay members noted that there had been no particular successes in public involvement and, again, this was sometimes linked to public apathy.

LM312: I would say we didn't have any really …

Many informants highlighted public awareness of PCGs as a success. The development of communication links with sectors of the community was another and this included public relations. For others it was specific projects such as health needs analysis. An increase in services within the primary care setting was also seen as successful, a number of specific projects were identified such as walk in clinics and up grading surgeries. Smith and Wilkin (1999) also identified the importance of creating links with the community and specific project success.

8.1.9 Lack of commitment & Inadequate Representation

Again public apathy was seen as a major difficulty in relation to involvement, limited resources either financial or time were also identified.

> LM529: … er well mainly I think public apathy, erm short of scandals, mass murders etc, the, the public aren't very interested in health …'

Some informants challenged organisational commitment and this extract perhaps typifies some of the difficulties (this area was explored further in Chapter Nine).

> LM312: There was no strategy, there was no budget, there was no will to talk about, I don't think they had the real will er to involve the public

Difficulties surrounding the territorial nature of separate agencies were also linked to public involvement issues.

LM183: … everybody's still protecting their patch, social services, district council, housing, health …'

Some general practitioners attitudes were described as negative and restrained, by others, self-interested and paternalistic.

LM202: GP attitudes really, sometimes (pause) I don't want to tar them all with the same brush, you know, a lot of the time they're fine, sometimes they're quite cynical erm quite negative about patients erm and feel that they're just been put upon all the time and that patients aren't particularly interested in kind of being more involved in their own health

Difficulties with adequate representation were also identified as well as concerns that such involvement may foster unrealistic service expectations

LM235: Probably the main obstacle is knowing how to get it, involving people without involving, without over involving individuals with axes to grind, getting a broad spectrum of users and to some extent non users …

8.1.10 Primary Care Trust Status & Public Consultation

In discussing future developments within the PCG, the majority of the organisations were projecting PCT status in 2002. 70% of the PCGs involved in the study had consulted the public on PCT status. Within the groups that had consulted the lay member had been involved in 70% of cases. However, of the lay members who identified involvement, the majority did so in a passive manner by attending meetings. Only 3 identified that they had been part of the planning process for public consultation (this theme is explored further in Chapter Nine). 10 out 12 PCGs had used public meetings for public consultation, 2 out 12 had met with CHC, 4 out 12 met with voluntary agencies.

8.2 Negative Interviews

Seven lay people were interviewed regarding their negative experiences as PCG board members – negative was defined as experiences, which fell beyond some of common difficulties experienced by lay members such as time limitations and workload. Content analysis revealed four distinct areas: -

- Role Development
- Skills Recognition
- Corporate Issues
- Relationships with General Practitioners

8.2.1 Role Development

A number of subcategories arose within lay members' discussions of their role: -

Validation

One of the difficulties was establishing a credible role within the PCG board. A lack of job description hampered progress and role definition.

> LM351: We didn't seem to have a job description, I mean there was an application form that I'd completed and there was a description in brief detail about taking the public view into discussion …

Such role uncertainty could be seen at PCG board level, through the reactions of other board members and the development of subgroups within the new organisational structure.

> LM411: Erm but as then the PCG developed and the work became clearer it was quite difficult really then to, to, how shall I put it, to get, to get the role of lay member to have any kind of er validity within what was going on in the organisation …

Such uncertainty was also visible in reactions to training sessions provided by the health authority.

> LM227: … they ran some training courses for us and the trainers, the trainers really didn't know what we were there for either. Nobody really seemed to be able to say 'right, this is the lay member, what we want from the lay member' …

Exploitation

Problems with workload highlighted within Phase One & Two were also discussed by some of the lay members such as the development of unrealistic expectations.

> LM227: I think they then started to expect far too much … they wanted me to write a couple of policy documents on public consultation …

The combination of a substantial workload with little job satisfaction also proved difficult.

> LM411: … looking back on it, I just felt a bit abused by it all really, you know, that er we were expected to do all this really but you felt that it was a token role …'

Isolation

As with many of the comments on the national survey, feelings of isolation again re-emerged with some of the interviewees, with the associated difficulties of being a lone member on a board dominated by clinicians.

> LM297: What you had, of course, on these PCGs was one lay member but you had seven GPs and two nurses so you had a broad representation of, you

know, of GPs, the problem as I say was really the isolation of the lay member …

Expectation

A persistent role expectation was that of public involvement, in some cases, lay members highlighted that this was the only area they were expected to get involved with This role at times was marginalised and unsupported.

LM269: … but they still regard erm community involvement as what I do, that's my job and they can, they can forget it

Linked with this aspect of their role were the perceptions of public involvement by other board members and the organisation as a whole, that the lay member equated public involvement, which at times resulted in distancing and relinquishing of responsibility

LM269: '… you've got to take public involvement seriously er for all sorts of reasons, firstly because it is, you know, it's a departmental requirement and secondly because you ought to anyway and er if you are going to take it seriously please don't think that it doesn't involve you and please don't think its just my responsibility …'

8.2.2 Lack of Skills Recognition

Another important area was the difficulty in having skills and previous experience recognised and acknowledged by other board members, particularly if these skills lay outside the medical domain.

LM411: We, we found it quite difficult to get anybody to recognise the experience outside of GPs, primary care, was actually valid …

On occasions other board members seemed surprised at the type of knowledge and experience held by lay members

LM264: I am use to handling very large budgets and I do understand financing, corporate financing and I think that that is something that has erm quite shocked them that I can actually give them answers when they ask questions of the finance people …'

The need for the opportunity to identify these skills was also highlighted

LM411: There should have been some opportunity at the beginning for people who weren't part of the medical cliché … for that person to be able to put forward their skills and experience …'

This was an area that was discussed with all the informants and within their discussions none of the lay members had a formal opportunity to discuss their skills and experience with other board members.

8.2.3 Corporate Issues

A number of organisational difficulties caused additional problems within the lay member experience. Changes in chairperson on the governing board could impact on role. Differing leadership styles had led to differing perspectives on the importance of public involvement as well as the level of inclusiveness afforded to the lay member

> LM411: … during my period as lay member we had three different Chairs and so the style of the PCG changed quite a lot, you know, between one Chair and another, and the first Chair who we had, just had that gift you like, being an inclusive person …

There seems to have been little support for chairs of the PCG discussed by these informants, with limited or no training offered. Such discussion also revealed an underestimation of the skills required to be an effective chairperson - often chairing skills were developed experientially

> LM269: '… there was no training at all for Chairs for any of the members and that I realised more and more that they have very little understanding of corporate decision making …'

PCG configuration had led to serious delays in the establishment and agenda of the organisation for some informants. An organisational preoccupation with Trust status was also seen as a hindrance, others criticised the lack of infrastructure supporting the new organisations. Smith and Wilkin (1999) also identified difficulties with infrastructure.

> LM227: I think when I joined it was something different than what I expected it was going to be, erm because I just had this impression that it would, some form of professional set up ready and waiting, which I felt wasn't there when I first got there …'

8.2.4 Relationships with General Practitioners

The majority of the discussion relating to relationships with other Board members focused on GPs. Only one lay member within this set of interviews described their relationship as particularly positive. Several issues were highlighted: -

Unprofessional Behaviour

One lay member in discussing a meeting with a group of users identifies unprofessional behaviour by GPs, either by absenteeism or apathy

> LM351: … and we went, only half the GPs turned up and of the half who turned up the other half went to sleep and all of these very brave people, not brave coz they got a disability but brave because they were speaking out and wanted to share their experience … but it was quite embarrassing even my own GP went to sleep and er it was just appalling behaviour.

In another example, general practitioners behaved aggressively to invited speakers.

> LM269: … we have had a number of meetings where, for instance, the chair of one of the other PCGs was quite severely savaged and was quite shocked. The Chair of the CHC came to give a presentation on er a new concept for training doctors i.e., putting patients first and getting, starting them off from year one in erm working in practice with patients, which is quite novel apparently and she was horrified and I was horrified by the reaction

Another highlighted area was the preoccupation of some general practitioners with remuneration

> LM351: Certainly in the first year we use to run a book on how many minutes it would be before they mentioned 'and what will our fees be?' I mean it was funny …

Lack of Corporate Identity

The above examples and those discussed within this session suggest that some general practitioners had difficulties in recognising their position within a structured corporate organisation and the accompanying corporate responsibilities, again this supports findings from Phase One & Two.

> LM269: what appears to me is that doctors feel that they are there to represent their own practices and that's not true …'

Medical Dominance

A strong medical dominance within the new PCG structure was highlighted by a number of the informants, such dominance took a number of forms such as meetings orientated towards GPs. Both, Smith et al (1999a) and Smith and Wilkin (1999) found difficulties relating to GP domination and professional attitudes.

LM351: The meetings were appalling, they had been use to, these group of men had been used to coming together and the chief executive just reported back to them …'

In some cases the persistent use of professional titles

LM227: Its quite interesting, you know, you can met anybody and you'll be introduced on Christian name terms, first names terms I should say this day and age, on first name terms but if you go to meet a doctor its always 'Oh this is Dr Smith …

Paternalistic attitudes were also identified within discussions, particularly in relation to the use of proxy by medical professionals

LM351: So er and I am a very confident person so felt able to put my twopeneth in, and put the community twopeneth in as and when needed, but the medical people really had great difficulty in understanding why, because they knew, they knew what their patients needed

8.3 Interviews with Non-Executive Directors & Chairs of PCTs

First Interviews (April 2001)

Thirteen non-executive directors and four Chairs took part in this first interview in April 2001, there was an open discussion with informants, emerging issues related to:

-

- Motivation
- Role Development
- Traditional versus Non-Traditional
- Views on PCT Governance
- Counter Strategies

8.3.1 Motivation

A number of reasons emerged regarding the motivation to move from lay member to non-executive director: -

Influencing the future

C373: I think it's because I'm enthusiastic about what a Primary Care Trust could deliver, erm I think it's properly the most basic reorganization of the health service that`s ever occurred.

The extract suggests a general enthusiasm for the new organisation. Continuing involvement was also seen as important and the ability, as lay people, to influence decision-making.

NED371: … the Board would effect more control, so that, you, you. I just felt, you know, it was er a, a good thing to do, try to improve things for people.

Continuity and Progression

The experience within PCGs was seen by some of the lay members as too short, there was a feeling that they were 'just getting started', that they wanted to continue with on-going projects.

NED325: Er, yes, well having done 2 years er as a lay member and got over the initial, sort of feelings that I didn't have much of a role to play, erm and then started actually getting something achieved, and getting involved with other things, I felt it was a shame at that stage er to give up.

Some informants saw moving from lay member to non-executive status as a natural progression, aiding continuity and that their experience would be a useful resource in the new structure.

NED529: I think we've started something, which if we continue will bare fruit in years to come, you know, if it seemed worthwhile and, of course, I could offer continuity.

Personal Development

The majority of informants identified their experience working within the PCG as positive and enjoyable, with good working relationships with PCG staff.

NED124: … one certainly was that I enjoyed the PCG experience, I got involved with a completely different set of people …'

Also more personal incentives for continuing involvement were identified such as personal commitment and mental stimulation

C360: … I, I am too early too retire and be brain dead so I needed something to keep me going and I thought it was damned useful'.

The position was also seen as a way of providing financial support

NED124: Secondly erm it provided me, having taken early retirement, a basic concept of being a board member or whatever, provided me with a. gainful part-time employment and b. erm, erm an extra slice of money on top of my pension.

8.3.2 Role Development – Traditional versus Non Traditional

The discussion of informants' perceptions and early experiences of the role of non-executive director revealed a complex and multi-faceted vision of their new position, represented visually in Figure 8.

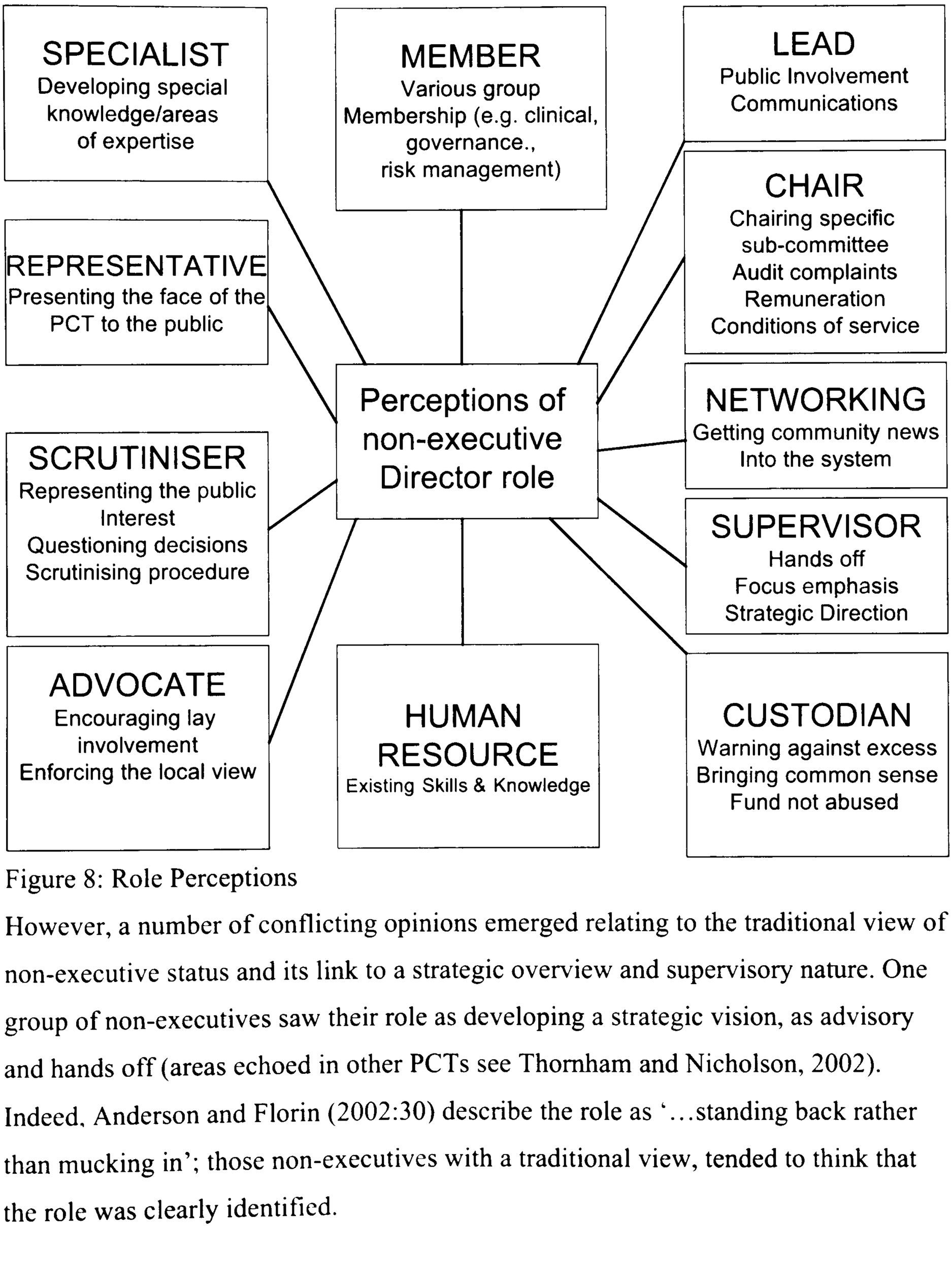

Figure 8: Role Perceptions

However, a number of conflicting opinions emerged relating to the traditional view of non-executive status and its link to a strategic overview and supervisory nature. One group of non-executives saw their role as developing a strategic vision, as advisory and hands off (areas echoed in other PCTs see Thornham and Nicholson, 2002). Indeed, Anderson and Florin (2002:30) describe the role as '…standing back rather than mucking in'; those non-executives with a traditional view, tended to think that the role was clearly identified.

NED321: ...its hands off to a great extent now, its much more about sort of developing strategic vision without necessarily getting too embroiled with the everyday things ...

This view of the non-executive directors role was also echoed by one of the Chairs

C547: The non-exes, well, they have an overarching view of where we're going, and they have some responsibility, in terms of, corporate issues.

However, some non-executive directors felt resistance to a perceived less 'involved and engaged' role than they had experienced as a lay member. Although there was acknowledgement of the need for a strategic approach, there was another group who wished to be directly involved and engaged within the decision-making process. The second description suggests a resistance to the traditional position and the wish to redefine the role of non-executive director. Informants who were more dissatisfied with the traditional role of the non-executive were more likely to highlight role confusion.

C540: Yes, now, its another interesting issue because erm we, we all had, had thoughts of, as to how the role of the non-exes in primary care should evolve, and we had discussions, the six of us have talked about it, how we see it developing erm and we're all committed and convinced that the, the non-exe role in Primary Care Trust is different to the non-exe role in health authorities and we see it been different by been more involved ...

NED536: ... I would feel that the PCT executive do, to some extent, see themselves as the decision makers with us rubber stamping everything, that's not the way I perceive it ...

In analysing these different perspectives, the divergence of views tended to focus the type, level and timing of involvement in the operational issues of the PCT. Previous experience, as lay member seemed to be important, particularly the level of influence they had attained. Some lay members had been involved with direct decision-making and some informants did not wish to give this up, however, as Anderson and Florin (2002) suggested the survival of this role would be unusual.

NED325: ... I think it's going to be quite different from being a lay member in that erm at least as a lay member I was involved in a lot of bread and butter stuff, which in future will be done er by the executive, rather than by the board ...

8.3.3 Views on PCT Governance

Three out four of the Chairs highlighted the uniqueness of the PCT structure. A specific issue identified was the lack of direct control over general practice in the purchasing and providing of services.

> C540: … its an interesting set up er I don't think there's anything else like it in the health area …
>
> C547: Its, its unique, we're in a unique situation where by there's no other er NHS Trust that works, that, that has done this sort of erm management erm strategic work or provided services …'

Many of the informants highlighted the lack of lay representation on the Executive Committee as a retrograde step and identified potential problems

> NED123: I, I think in one respect it's a very retrograde step. I think, I think it's the whole, my feelings about the whole structure, is this is the weak point. And I feel very strongly that the clinical executive will, although it doesn't have the ultimate power, it will have the main authority and we've now lost the kind of lay membership of that.
>
> NED536: …what does worry me is there isn't any lay representation apart from CHC on the executive …
>
> NED176: …the professional executive are not really engaging with public involvement that much, that's one of the weaknesses of not having lay membership on it.

However, not all respondents thought the lack of lay representation was a problem.

> NED529: The overview, if you like, should include lay members, I think the day to day running of the thing should not, does not need lay members present because day to day running of the thing is a executive matter …

The Chairs of the board had a united vision of what its role was - strategic and overarching responsibility.

> C540: … the Board has this overarching responsibility and er makes the decisions in principle and that kind of thing …
>
> C373: I think, er, er, er I think the, the Board is clearly set up to set an overall strategy for the PCT and clearly, in fact, that's going to impose certain requirements on the clinicians …
>
> C360: The Board basically starts off with the role of being, well this is good British constitutional law isn't it, being the checks and balances bit …'

Other non-executive directors also identified this role.

> NED273: … I see the Board erm as, as representing strategy, saying that this erm this is where I want to go …

One informant embraced the board structure, having a majority of lay members, which would reduce feelings of isolation felt on the PCG board.

NED184: …from my point of view I was looking forward to going on to a Board where there was going to be five or six lay people there, erm who would all bring different skills …

Others, though accepting of the strategic role of the board, wanted to develop its remit further.

C360: … we'd like to see particular the non-executives of the board used more as a resource. So we all want to be involved in particular interests and particular development groups as they come along.

One informant was particularly uncomfortable with the role of the board.

NED124: …there's nothing to talk about, there's nothing really, you cant, I don't think the six of us as non-exes could turn round and say, or at least we haven't yet, turn round and say 'no we don't like that', 'we don't think that's a good idea' erm it doesn't, there doesn't seem to have been erm argument, discussion, weighing up different options and so on, it all seems very, er officers lead, Board approved at the moment.

Different levels of responsibility were identified such as increased power as well as the need to ensure probity and transparency within the decision-making process.

NED124: … its obviously got massive responsibility, don't get me wrong. We know that we've got to approve this, that and the other, we know we got to check on the probity and the openness and all that …

NED123: Yeah it's more different from the lay member role than I had anticipated. Erm I think because, because the non-exes form a large block on the new Primary Care Trust boards, they, they have very much more kind of responsibility and power.

Another role of the board was internal and related to skill mix. The focus was on the importance of a mixture of skills, experiences and abilities from non-executives and Chairs in supporting its work.

C360: Yes. I mean, there's a gender balance, there's three men and three women for a start, most of them are my age group, although we've got one young woman's who's a young mum, who's sort of 25 years younger than the rest of us, which again is a nice balance. There's people from er from business backgrounds. I was originally social services, there is one person who was a nurse, erm and as I say, this other young lady who is actually a young mum interested in public affairs. So it's quite a nice mixture.

The executive committee was perceived as having the main responsibility for day-to-day operational issues and technical and clinical decision-making.

C540: Erm the theory of the Executive Committee being the 'engine room' if you like [yes] and making the er technical decisions and er health decisions, whilst the Board has this overarching responsibility and er makes the decisions in principle and that kind of thing, it …'

8.3.3.1 Discourse Analysis

It was clear from the transcripts that the majority of non-executive directors, involved in this study, disliked the change of identity indicative with this new role. Government rhetoric was seized upon, which related to the description of the executive committee as the 'powerhouse' or 'engine room' of the Trust. Non-executive directors used these terms repeatedly to highlight concerns over the loss of decision-making powers. Discursive practices have a historical specificity (Clegg 1989) and the role of non-executive director, itself, has an historical ontology, emerging from corporate culture. Chapter Two highlights the expectations of non-executive directors clearly, however, interestingly, the majority resisted this established identity.

The Engine Room

There were concerns that the term 'engine room' would be manipulated by the Executive Committee and this is resisted in this extract with the use of the term 'main Board'. Although in reality there is only one Board, the term suggests Board authority and the ability to direct decision-making.

> NED371: …the Executive Board has been told that it's the 'engine room' and that's been in government papers, that's the place where the work is going to get done. I think that they will construe that er as that they are gonna be **it …** and I don't think that, that is the way its going to be, I think that the main Board will certainly wish to give them directions and expect them to action those directions …

Others developed the analogy, placing the Executive Committee below the Board. The engine room is depicted within the imagery of a ship, with the Executive Committee below board, a subordinate class. The Trust Board is placed in higher position on the bridge, having control and direction. The metaphor of government likened to a ship was also identified by Foucault (1978), where governing not only incorporates taking charge of the cargo, sailors and boat, but also reckoning with all possible events.

> NED544: … referring to it as the 'engine room' actually suggests that the engine room is down below and the Captain of the ship is above with his officers, so it, sort of, inferred that the Board was on the, you know, having the clear overall vision, giving stuff down to the Executive to handle on their behalf …

Rubber-stamping

Many of the respondents reacted to the 'engine room' analogy and were keen not to be involved with 'recommendation to approve'

> NED536: ... they'll see themselves as, as preparing all data and giving it to us to rubber stamp, I'm not that sort of person, I will be asking an awful lot of questions on behalf of the lay person ...'
>
> NED147: ... we do not wish to be a 'rubber stamping' exercise so we've got to devise new ways, means and links of keeping closely in touch with the erm primary care development issues ...'

Within these accounts the executive committee members are de-personalised with the use of the terms 'they' and 'the clinicians' and in other discussions the Executive Committee is renamed and described as the clinical executive.

In analysing the extracts, there is resistance to the potential loss of direct influence and involvement in decision-making as well as how certain decisions would have been reached – all areas focus on the loss of control of information. Overarching responsibility and strategic development is obviously not seen as attractive as direct and active involvement in clinical and operational decision-making. This is also emphasised within the non-executives' discussions of PCT governance with the lack of lay membership on the executive is seen as retrograde, a missed opportunity (see Section 8.3.3).

8.3.4 Counter Strategies

In discussions with non-executive directors and Chairs, a number of counter strategies were identified that had the potential to gain access to decision-making processes, or at least have the ability to block such decisions: -

- Redefining the role of non-executive
- Joint working and subcommittee membership
- Legitimatising authority
- Use of lay majority

In some instances, this led to a re-defining of role, to a new emphasis on active involvement. Further role development can be seen as non-executive directors start to develop areas of interest and expertise.

> C540: ... we're all committed and convinced that the, the non-exe role in Primary Care Trust is different to the non-exe role in health authorities and we see it been different by been more involved ...

Joint working and subcommittee membership had the potential to facilitate lay involvement at an executive level as well as enabling earlier access to decision-making and the ability to influence policy. Anderson and Florin (2002) and Thornham and Nicholson (2002) also highlight the importance of subcommittee membership suggesting that such groups provide opportunities to contribute and make a difference as well as giving an in-depth understanding of issues before they arrive at the PCT Board. For some this strategy extended to placing non-executive directors in all subcommittees, the result would be to dramatically increase the board's access to information

> NED536: … there's got to be a lot of questioning and a lot of involvement, that's why all the non-exes have said we want to be involved at executive level by chairing committees.

Attempts at legitimatising authority can be seen within discussions with some informants. Their appointment by central government, a higher authority, was utilised as a strategy for supporting claims in relation to increased involvement in decision-making. This was sometimes personalised by using the term Secretary of State.

> NED544: … my appointment is that I am, you know, according to the letter, personally responsible to the Ministry of State, who is ensuring that the work of the PCTs is carried forward, now that means I'm not prepared just to put my name to things unless I have some understanding of it …

There was also recognition of the potential power of a lay majority on the Board of the PCT as a vehicle to block discussions made by the executive committee.

> NED123: Erm I mean I think the scenario that worries me is that the clinical exe might put a lot of time and energy into thinking through a particular issue and then make a whole set of recommendations that the Board rejects because they haven't been part of the process.

However, in discussing overall experiences with non-executive directors after six months within post, there was still a perception that real power lay with the Executive Committee and that they continued to have little influence.

> NED273: … I felt that we were still being very much under the control of the officers and the exe directors, which disappointed me somewhat …
>
> NED124: … we've never met I couldn't tell you whose on it, I know, well I know some of the people who are on it but erm there's been no er occasion where the Executive Committee and the Board are in the same room at the same time …

Even the minutes of the executive committee are problematic; they were at times withheld or were constructed in such a way as to make the information difficult to

interpret. Recent reports show continuing difficulties in influencing areas such as local service development (Appointments Commission 2005).

8.4 Final Interview

Third Interview (October 2001)

As with the first interviews, thirteen non-executive directors and four chairs took part in this final interview in October 2001. There was an open discussion with informants focusing on a number of areas, the following areas are presented within this chapter: -

BOX 33

Subject Areas of Third Interviews

- Reactions to policy changes
- Patient Advisory Liaison Services
- Patient Forums
- Voice
- Expertise & Training
- Relationship with Executive Committee

8.4.1 Reactions to Policy Changes

Non-executives and Chairs were asked for their reactions to recent policy changes, particularly surrounding government documentation such as 'Shifting the Balance' and 'Patient and Public Involvement'.

Positive Reaction

The majority of informants interviewed viewed the recent policy changes positively and welcomed the increased emphasis on public involvement.

> NED371: I think the general feeling is that erm the move is in the right direction (yeah) but there seems to be an awful lot of stuff coming, sort of a bit of an indecent pace really …'

However, not all were convinced about the government changes

> NED325: I'm beginning to think that erm they're using a sledge hammer to crack a nut (yeah) I personally find all of the stuff coming down from the department extremely frustrating and irritating …

Continuity and Change

A number of concerns were voiced regarding the pace of policy change and its relentless nature. Some concerns focused on the limited timescale to incorporate the changes, as well as a potential loss of a local perspective through absorbing health authority responsibilities.

> NED544: … there's such a huge agenda (yeah) erm that to some degree there's a feeling that we've lost the local perspective about it. The agendas are coming from government without giving us time to sort of really interpret it locally and make a difference

Other informants wondered how the changes would be operationalised, persistent policy change was linked to organisational capacity and also identified as a vehicle for potential distraction.

NED529: … it all sounded wonderful on paper, it was only when people began to consider how the heck we do it that it began to dawn on them that was not going to be than simple …

NED285: … it feels like you're consistently being bombarded with change, which is wonderful I have no problem with change but I don't think that the structures are robust enough to cope with that …

The need for a period of consolidation and some continuity seemed important.

C360: … its just seems as if we only just manage to keep running to stand still (yeah) we were a PCG and we'd not been in existence long before we became a PCT and we've only been in existence six months and we're already talking about what happens next year erm I just want a bit of stability …

8.4.1.1 PALS

There was a mixed reaction to the development of PALS with issues relating inactivity and operational difficulties.

Inactivity

Out of 17 informants interviewed, seven of the PCTs in which they were involved were still waiting for guidance from the government, policy ambiguities surrounding the implementation of this service surfaced as a reason for delay

NED123: … I mean the government hasn't yet made its intentions totally clear except in this new paper, which I have to say, I've actually haven't even read this is the discussion document involving patients and the public in health care (Yeah) so the simple answer we haven't moved with it yet

NED124: … I've E-mailed our chief exe the other day and said er I think, I just put something on 'what are we doing about PALs?'

For some there was an unwillingness to pre-empt government dictates

NED371: … we don't want to do something and then find its not what, you know, we've just wasted our time as it where

Operational Difficulties

A major criticism of the new service was a perceived lack of thought within government policy regarding its operationalisation within primary care. Lack of financial support from government was also highlighted, with suggestions of potential cuts to other areas to support the service

> NED544: … what I'm still trying to come to terms with and awaiting guidance on, is how the hell its going to work in primary care …'
>
> NED325: … we can't afford, as a PCT, to fund PALs and a Patients Forum ourselves, because we just haven't got the resources to do that, if we do we are going to have cut back on, on surgical procedures and goodness knows what …

For some, attempts at partnership working with the acute sector had already failed in relation to developing PALS.

> NED321: … we should have been further a head than we are, but we attempted to do it partnership with the erm NHS Trust hospital and fell apart (right) I think their versions of PALs and ours were somewhat different …

8.4.1.2 Patient Forums

Existing structures and partnerships

Some of the PCTs had starting developing forums using existing structures, which included partnership working with local CHCs.

> NED325: For the past 5 or 6 months I've been working with the locality group of the Community Health Council in erm drawing up a process and proposals for a Primary Care Group, er Patients er Forum …
>
> C547: We were fortunate in that, as much as we'd got a group of people together, a group of 20 together that erm are, have been doing some voluntary work for us …

Operational Difficulties

Again, a number of concerns were related to the development of forums, such as logistical problems linked to the number of people required for these structures as well as their reactive nature.

> NED147: … patient forums not being so much bottom up but actually been in a reactive role to evaluate, comment on, monitor instead of what most patients want to do, is to be able to start with their agenda, at their pace and feed something in appropriately …

Some gave more sceptical views relating to their formation.

> NED176: I think secondly erm the patients forum will very probably be the community health council under a new name (right). I think er they are

committed to abolish CHCs erm but realise they've got to find a way of appeasing people …

8.4.1.3 Voice

Government proposals of developing the structure 'the voice' at a strategic health authority level came in for the strongest criticism. There was some questioning of the necessity of this structure and again concerns about how it was going to be operationalised.

NED147: The national voice, I have to say, we're trying hard to find some positive elements within it but I almost wonder if there is a real need for this body…

C360: I mean I'm not entirely sure if I really understand what the local version of Voice is ...

There were also concerns regarding the effectiveness of this structure, again the loss of local focus was seen as a potential problem.

NED176: …I'm just not sure really how effective Voice will be, it seems a little bit like trying to make best sense of, of having strategic health authorities and having to link up with them …

NED544: … our local voice, erm as they call it, you know, covers the new regional strategic health authority which is like most of the north of England (right) so, you know, how that can relate to the locality …

8.4.2 Expertise & Training

Informants were asked about whether there was a lead for public involvement that was a salaried person within the PCT management structure. Results mirrored data from the studied primary care groups - with a lack of expertise in senior positions or an additional responsibility within a pre-developed job description. Only one PCT had a director for public involvement, this position had been advertised locally, however, was re-advertised nationally to gain the appropriate calibre of candidate.

NED544: … unless somebody at a director level is given overall responsibility it ain't going to happen …

Similar results were found in relation to training. There had been no planned formal training sessions for any of the four chairs interviewed. A number of informal routes were identified, which aided their developing role such as support from the Chief Executive and Chair of the Executive Committee as well as reliance on previous experience both as a lay member and chairing meetings.

> C540: … well the difficult bit is the lack of support er training (yeah) or guidance from regional health authorities or the centre for people like myself and other non-exes

2 out of the 13 non-executive directors described their training as good, 6 of the non-executive directors had no or little specific training to help support their role. A number of difficulties were identified within this discussion area such as the use of external training consultants, however, others had self-initiated sessions.

> NED124: … I do find sometimes when these people come along and facilitate and they say 'what we're going to now is ask you what you think the role of a non-exe is' and then everybody chips in and at the end of it all you write down what everybody else has said so you still really haven't developed the role of the non-exe, you've only picked the brains of the other people who don't know anything either!

8.4.3 Relationship with the Executive Committee

Distant Relations

Many of the informants describe the relationship between the board and executive committee as distant. The main area of difficulty focusing on effective communication links between the two structures, the lack of communication had led in some cases to frustration over the duplication of work

> NED124: … there's been no er occasion where the executive committee and the board are in the same room at the same time …
>
> NED176: Well, I, I suppose we had one away day together in May (yeah) and as two groups we've had nothing to do with each other since (right) it isn't that we are growing apart, we're doing different business and they get our minutes, we get theirs, our only link are the people who are common to both, the chief exe, the director of finance, one or two of the directors erm a couple of doctors and so forth.
>
> NED285: …I have to ask again for the minutes of the last meeting, because we don't get them automatically and we've talked about rotating non-exe directors so we could go along to their meetings er I haven't been yet, so its not been my turn I suppose, so basically there's no formal process there and it does feel like there's two separate committees running …

Medical Dominance

Other non-executive directors note difficulties with medical dominance and a preoccupation with clinical issues

> NED321: … I think they're very erm professionally orientated, the GPs particularly towards their work as clinicians …'

However, some had developed a positive relationship between the two structures, the relationship between the chair, chief executive and chair of the executive committee identified as important

> NED184: We're getting together really well, actually erm I think, I think its still early days I think, I think what is good though there seemed to be quite a good erm working partnership between the Chair, the chief executive and erm and the Chair of the PEC and I think that's sort of filtering down …
>
> C540: Well its very, very good, I mean, the three at the top as far as our trust is concerned is excellent

Strategies for Inclusion

As in the first interviews, some non-executives continued to develop strategies to counteract difficulties with communication and lack of perceived influence

> NED123: … we've now decided the Chair of the board will go to the clinical executive meetings, I think that's quite a good move and we get, we get copies of each others minutes so we know what's, what's going on …
>
> C360: We have built in now, we run a series of joint development meetings to start with (yes) and we have informal meetings on a bimonthly basis …

Summary

In evaluating the interviews with leads in public involvement it revealed informants having rewarding experiences. However, there were also frustrations, the data analysis identifies concern focusing on the number of replicated historical difficulties relating to involvement. These include: -

- Limited strategic development
- Preoccupation with consultative and information giving methods
- Public involvement failing to capture a senior management position
- Perceived lack of commitment and effectiveness
- Lack of resources
- Multi-agency dominance of public involvement subgroups

It became clear that there was a need to attempt to explain these cases of 'history repeating' – why did so many barriers to participation remain intact and difficulties

left unchallenged? Chapter Nine utilises Foucault's concepts of governmentality and discipline to examine these questions. Discussions with informants regarding their negative experiences also assisted in a number of theoretical developments relating to power. Revisiting transcripts saw issues of visibility and invisibility emerging (Foucault 1977b), lack of job description, lack of acknowledgement of skills tended to impact on these individuals and their visibility as lay members within the PCG structure. Medical dominance, the disregard for lay perspectives and the use of professional titles enhanced this invisibility. Although, interviews with non-executive directors identified the importance of continuing involvement in their organisations' evolution, it is the sphere of influence and the perceived constraints of their new roles that brought areas of conflict, particularly, focusing on the level of active involvement in operational matters. Again, transcripts focusing on this debate in the first and third interviews were re-analysed using the conceptual framework with the results presented in Chapter Nine.

CHAPTER NINE

A Conceptual Framework for Public Involvement in Primary Care

Introduction

This chapter represents the analysis of the final phase of the research and utilised specific data from Phase 1, 2 & 3, which provided complex and sometimes conflicting perspectives on public involvement in PCG/Ts. Particularly important was trying to address why the concept, a policy directive, failed to progress significantly over the two-year data collection period, with many of its historical difficulties replicated. Chapter Nine incorporates a conceptual framework in attempting to explain some of these conflicts utilising Foucault's concepts of governmentality and discipline. Firstly, it is suggested that governmentality embedded in policy directives and national targets negatively impacted on the local development of public involvement. Secondly, the data reflected the influence of disciplinary instruments and panopticism within the new primary care organisations, which impacted both on the way public involvement was developed and who became involved. Often the effects of governmentality and disciplinary mechanisms were the invisibility of public involvement, with themes of visibility and invisibility evident throughout the data analysis.

The research identified a rapid pace of change in primary care, which contrasted with the slow (sometimes non-existence) development of public involvement in the period 1999 to 2001. Health policy (DoH 1997, 'The new NHS Modern and Dependable'), which advocated a local decentralised autonomous approach, seemed to undermine itself with central directives that impacted on local organisations and managerial/professional behaviour, often to the detriment of active lay involvement. Furthermore, the national survey, case studies and interviews presented in this study revealed another replication of the 'usual suspects' in lay terms (see Tables 1, 2, 3 & 4 Chapter Six), both individually and as the composite bodies of working groups (see Section 8.1.5). It is suggested that such subjects are historically less likely to challenge existing power structures (Richardson 1989) and more likely to act as docile bodies, agents who carry out central determined objectives (Foucault 1977a).

9.1 Method

A number of conceptual frameworks were considered for the re-analysis of specific data from Phases 1, 2, & 3 (2004 – 2006). One such approach, Lukes Three Dimensional Model of Power (Lukes 1974, 2005), would have proved useful in explaining evidence relating to specific decision-making events within PCGs. Concepts of non-decision making and mobilisation of bias (Lukes 2005) provided credible explanations of incidents where there was evidence that lay members and community working groups had been sidelined. However, the three-dimensional model showed limitations in its potential explanation of the impact of government directives on organisational behaviour and its ambiguity in relation to elements of resistance identified within this research. Ultimately, this model was rejected in favour of Foucault's concepts of governmentality and discipline, which were considered more comprehensive and provided a more detailed exploration.

The concepts of governmentality, disciplinary power and resistance represented a direct and clear application to the study's findings. Foucault's work on governmentality provided a detailed discussion and explanation of the paradoxical nature of government policy-making. Other potential explanations, such as Lukes Three Dimensional Model of Power, lacked a sophisticated argument – government tactics and strategies, with the incorporation of primary care institutions, moved beyond discussions relating to decision/non decision-making. Clegg's (1989) assessment of the third dimension of power as ambiguous seemed supported by these observations, with Foucault's work offering a more comprehensive description of the operationalisation of this form of power. Foucault's discussion also offered an explanation for why such disparity occurs, focusing on need to maintain social stability and a status quo (see Section 9.2).

The choice of a Foucauldian approach was also influenced by the impact of Foucault's work on the field of health studies, evident through the literature review. This approach can be seen in numerous research studies, some are specific and important to this study. For example, Hughes and Griffiths' (1999) examination of contracts and commissioning, Light's (1999) views on managed competition in the NHS and Joyce's (2001) analysis of priority setting. Lynch (2004) utilises the approach to provide an explanation of managerial behaviour in relation to national

targets. Cant and Sharma (2002:341) also discuss aspects of governmentality, again, the authors identify the disparity between the notion of 'rolling out the state' and the increase in government legislation and regulation in relation to the provision of specific health services. Nettleton (2006:117) also makes an association between governmentality and policies on clinical governance.

As data continued to be re-analysed it became clear that issues of power and dominance were operating on multiple levels. The analysis outstripped the Three Dimensional Model under review at the time (see Lukes, 1974, 2005). This theoretical framework strained to provide adequate explanations, particularly in relation to the low visibility of the new NHS organisations in the public arena and how managerial behaviour was shaped and controlled. An in-depth review of Foucault's 'Discipline and Punish' (1977) highlighted the role of disciplinary mechanisms in producing and maintaining docility and utility. Such disciplinary power is most evident in social institutions (Nettleton 2006:117). This concept offered a credible and detailed explanation of why individuals were behaving in certain ways within NHS organisations. McDonald (2004) also utilised a Foucauldian approach to explore issues relating to the control of employees and their identities within the context of PCTs.

Another important area pertinent to the research findings was the concept of resistance. Within Lukes Three Dimensional Model there is very little reference to resistance, some other models focused on collective struggle. The plausibility of collective struggle against medical dominance and central policymaking seemed unrealistic. Foucault offers a very different view of resistance, where power relations are intrinsically linked to resistance; such resistance is focused where power is exercised (Foucualt 1977a). This viewpoint had the potential to impact on relations between health professionals/managers and members of the public. Again, Nettleton (2006) makes direct links between this Foucauldian concept and professional/lay relationships, identifying that within this interaction the patient can show evidence of resistance. Within this interaction, patients can determine the level of disclosure and the extent they follow health advice given. Similarly, Luker and Speed (2006) identified issues of resistance in their research into power relations between district nurses and general practitioners.

9.2 Governmentality & Discipline

In this section Foucault's theories of governmentality and discipline will be presented. This is a complex body of work and in order to do some justification the following pages attempt to cover a range of major concepts that are relevant to this study. In Section 9.3 the relationship between the governmentality and the NHS is presented, subsequent sections bring together theory and the effect on public involvement that demonstrate how governmentality has impacted on the implementation of policy on public involvement in studied PCG/Ts. Section 9.6 identifies the impact of disciplinary mechanisms on areas such as recruitment, role development and public awareness, again, highlighting the impact of discipline on public involvement. The final section examines areas of resistance found within the research study, such as resistance to subjection and the development of initiatives beyond surveillance.

Foucault (1978) in his essay 'Governmentality' describes the historical development of the art of government identifying it as a multi-dimensional concept and a complex form of power. Within this discussion there is a differentiation between sovereignty and governmentality, the aim of the former is identified as the common good and obedience to the law, governmentality presents as more ambiguous focusing on the employment of tactics, arranging things in such a way through certain means so that certain ends are achieved (Foucault 1978:209). Its diffuse nature is evident as Foucault (1978) links governmentality to a mixture of institutions, procedures and tactics that facilitate power with its target the general population. Foucault (1978) also described this power as superior to other forms of power. This domination and management of the population occurs not only at a collective level but also through the control of individual bodies via disciplinary techniques (Foucault 1978, Lynch 2004).

Foucault (1978:205/206) maintained that government practices were 'multifarious' focusing on many kinds of people and identified three types of government – self government, economy and politics - governmentality is characterised by the continuity of these typologies, working in both upward and downward directions. Upward continuity is linked to governing oneself before governing the state, downward continuity suggests that individuals will behave themselves if the state is run well (Foucault 1978:207). Dean (1999) describes this as the 'conduct of conduct',

it portrays a dual meaning – on the one hand to lead or direct, the other focusing on self-guidance and self-regulation. Dean (1999:10) suggests that the concept includes '… any attempt to shape with some degree of deliberation aspects of our behaviour according to a particular set of norms and for a variety of ends'.

Important to this research study are Foucault's discussions on management of the population as the NHS serves such a population. Historically, Foucault (1978) identified that the emergence of statistics and its ability to identify problems specific to the population led to a refocusing away from the family, the purpose of government becoming the welfare of the population. Government acts on the population either directly through large scale campaigns or indirectly via techniques and tactics without the population being fully aware, here the population is both the subject and object – ' … aware of what it wants, but ignorant of what is being done' (Foucault 1978: 217). Furthermore, governmentality functions internal and external to the state as the ploy of government is to continually define and redefine what is within the remit of the state and what is not (Foucault 1978:221).

In discussing health policy Hughes and Griffiths (1999:71) define governmentality in terms of acting or steering at a distance believing this is displacing traditional bureaucratic regulation of the service and providing alternative forms of de-centralised governance. Such governance by subtle manipulation or via discourses and technologies can come to permeate social networks and Hughes and Griffiths (1999:89) describe the effects of governmentality on the service as more complete and all encompassing, overriding control by organisational rules or commands from superiors. Furthermore, Lynch (2004:131) suggests that NHS policymaking over the past 20 years regardless of political doctrine has been the means to maintain or increase discipline and to strengthen the status quo on behalf of the government.

Also of relevance to this research is Foucault's exploration of disciplinary instruments, panopticism as a vehicle for discipline and the disciplinary society, with its emphasis on utility and docility. Foucault (1977b:170) suggests that the main function of disciplinary power is to train, it is a specific technique of power that views individuals both as objects and instruments of its exercise, he describes it as '… a modest, suspicious power, which functions as a calculated but permanent economy'.

For Foucault (1977b:221) discipline reduces the body to a 'political force' with the emphasis placed on docility and utility, bodies via corrective training can be maximised as a useful force whilst continuing to be dominated. The success of this form of power is linked to three instruments – hierarchical observation, normalising judgement and the combination of the two described as the examination.

Hierarchical observation is seen by Foucault (1977b:173) as coercive and is associated with his discussions regarding the Panoptican (see Section 2.14) suggesting that '… the perfect disciplinary apparatus would make it possible for a single gaze to see everything constantly'. His discussions moved its use beyond the penal system and incorporated the military camp, school, factory and hospital with the emphasis on the threat (real or potential) of constant surveillance, which was enough to ensure self-regulation and docility. Although Foucault (1977b:174) identifies the role of supervisors within such surveillance - specialised personnel distinct from workers, he emphasises the insidious nature of discipline via surveillance highlighting that even observers are observed, within this scenario disciplinary power can become an integrated system.

'It was also organised as a multiple, automatic and anonymous power, for although surveillance rests on individuals, its functioning is that of a network of relations from top to bottom, but also to a certain extent from bottom to top and laterally …' Foucault (1977b:176/177).

Foucault (1977b:184) identifies another disciplinary instrument the normalising judgement – 'normal' is established as a principle of coercion, and like surveillance, normalisation becomes a great instrument of power. Foucault (1977b) describes this instrument as a small penal mechanism, which falls outside the formal penal system. There are norms surrounding areas such as time, activity, behaviour, speech and the body – for example, appropriate times to start and leave work, non-conforming is punishable and often linked to penalties (Foucault 1977b). Foucault (1977b:183) identifies the gratification punishment continuum, this is a continuum of behaviour from good to bad, the disciplinary apparatuses can hierarchize good and bad subjects in relation to one another. This involves ranking and judging according to aptitude

and conduct, here, there is constant pressure to conform to the same model so subjects might all be like one another (Foucault 1977b).

The examination combines surveillance and normalising judgement suggesting that 'It is a normalising gaze, a surveillance that makes it possible to qualify, to classify and to punish' (Foucault 1977b:184). Such a normalising gaze establishes a compulsory visibility over individuals, visibility assures the hold of power over them as the examination locks them into a mechanism of objectification (Foucault 1977b:187). By contrast, disciplinary power is exercised through its invisibility, whilst visibility of individuals enables differentiation and judgement (Foucault 1977b:187). Importantly, Foucault (1977b) suggests that the examination also incorporates documentation as well as a field of surveillance. Aspects of this theoretical discussion have and can be related to health policy, for example, the use of performance indicators, the use of such tools as league tables and standardised waiting times, all increase NHS Trust visibility and allow comparison against a given norm and against other health trusts (see Section 1.16).

Furthermore, Foucault's (1977b:205) discussion moves beyond the concrete and architectural example of Bentham's panoptican (1843) suggesting that the concept is 'polyvalent in its application' and the 'panoptic schema' can be utilised when dealing with a multiplicity of individuals on whom a task or a particular form of behaviour must be imposed. He introduces the term 'panopticism' - 'a figure of political technology that may and must be detached from any specific use' (Foucault 1977b:208). Again the concept is aligned to discipline, panopticism shows how to '… unlock the disciplines and get them to function in a diffused, multiple, polyvalent way throughout the whole social body' – allowing disciplinary mechanisms to infiltrate society (Foucault 1977b:208/209). Whereas as the panoptican functions as a discipline blockade through an enclosed institution, panopticism is a functional discipline mechanism, a generalised surveillance that improves the exercise of power by making it lighter, more rapid, more effective, a design of subtle societal coercion (Foucault 1977b:208).

Foucault (1977b:210) also describes how certain processes can extend disciplinary institutions moving towards a disciplinary society: -

- Functional Inversion of the Disciplines
- The Swarming of Disciplinary Mechanisms
- The State-Control of Disciplinary Mechanisms

Discipline moves from neutralising dangers to increasing individual utility with disciplinary mechanisms breaking free, becoming de-institutionalised with increasing adaptability and flexibility e.g., disciplining – going out into the community, giving and receiving information (Foucault 1977b:214). This is linked to PCG/Ts community activities in Sections 7.3/7.9. Disciplinary mechanisms can also be taken over by pre-existing authorities as a means of reinforcing or reorganising their internal mechanisms of power (Foucault 1977b:216). They also can be taken over by state apparatuses in a bid to assure that discipline controls society as a whole and Foucault (1977b:217) goes on to identify growing state influence suggesting a profound intervention in all details and relations of social life.

However, conversely, Foucault (1977b:215) maintains that it would be wrong to believe that the disciplinary functions are confiscated and absorbed by the state apparatus, discipline remains a type of power compromising a whole set of instruments with many levels of application. Foucault (1977b:222) gives the example of societal systems such as the judiciary, although based on egalitarian principles, such systems are supported by minute, everyday, physical mechanisms, systems of micro-power that are essentially non-egalitarian and asymmetrical, here, discipline acts as a counter law, guaranteeing submission. Foucault (1997b:223) suggests that minute disciplines, the panopticisms of everyday, work below the level of apparatuses and great political struggles, they are the very foundation of society, an element in its equilibrium and also form part of a disciplinary society. This is discussed further in Section 9.6 and relates to the recruitment process for PCG/Ts.

Foucault (1977b:218) also identifies and discusses the formation of a disciplinary society, with a number of power tactics to maintain such a society - the exercise of power at the lowest cost possible, to maximise and extend the effects of this social power as far as possible and to increase both the docility and utility within the system.

Foucault (1977b:135) places a strong emphasis on docility and utility suggesting the notion of the body as an object and target of power, here, as stated earlier, the body can be manipulated, shaped and trained, to respond and obey. Foucault (1977b:137) suggests that this takes the form of a subtle disciplinary coercion, in a societal context, such discipline not only produces obedience but also increases its usefulness. Foucault (1977b:140) identified four disciplinary methods/techniques: - the art of distributions, the control of activity, the organisation of geneses and the composition of forces, all discipline and control the body – some of these methods are discussed in the next sections in relation to primary care and the effects on public involvement.

9.3 The NHS & Governmentality

In analysing the series of guidance establishing PCGs a limited timescale was given to health authorities and health professionals to organise governance, operational procedures and national health improvement targets.

The following cut-offs dates included: -

BOX 34

Early PCG Objectives and related Timescale

- Proposed configuration of PCGs to be registered by July 1998
- Shadow PCGs in place by September 1998
- Key members of the governing board established by October 1998, a first year action plan devised by November 1998
- PCGs and health authorities to have identified one national and one local health improvement priority by December 1998
- Registering an interest for Trust status and developing a Primary Care Investment Plan (PCIP) by January 1999.
- Three-year plan to be established by September 1999

Foucault (1977b:150) identifies the timetable as an element of disciplinary coercion encompassed in the disciplinary technique identified as the control of activity (see Section 9.2). Foucault (1977b:150) suggests that the partitioning of time not only facilitates domination but also attempts to assure the quality of the time utilised, again emphasising a mixture of docility and utility – here, power is articulated onto time, assuring its control and guarantees its use. Time assurance is linked to both supervision and pressure, with the elimination of areas that disrupt and disturb (Foucault 1977b:150). Such an explanation can be used to interpret government guidance and the development of PCGs. National guidance provided a mixture of supervision and time pressure, Box 34 and the literature review (see Chapter Four) showed the absence of public involvement within this drive for an efficient organisational transformation (see DoH 1997 'The new NHS: Modern and Dependable, HSC 139, 1998).

An explanation for the slow start of public involvement strategies, particularly within the case studies (see Sections 7.2 & 7.8), is that this area was seen as disruptive or as Foucault (1977b) would describe as 'invalid' within this disciplinary mechanism. Interestingly, the government could have used the public involvement strategy as a self-governing mechanism (Hughes and Griffiths 1999), however this area was left unsupported in terms of definite timeframes or specific objectives suggesting this was not a dominant discourse operationally at this time.

Foucault (1977b:160), in his discussion of the organisation of geneses, suggests that disciplinary methods reveal a linear time, an orientation towards a terminal, an 'evolutive' time. This potentially links the rapid pace of change inflicted on new primary care structures to disciplinary coercion, as this method manipulates behaviour towards this terminal state, with a seriation of successive activities, which allows the possibility for detailed control and regular intervention (Foucault 1977:160). Seriation, or a series of levels, related to time and activities inflicts tasks that are both repetitive and different but always graduated (Foucault 1977b:160). This can not only be used as an explanation of the evolutionary nature of primary care, which was government-led, but also the identified replication of work within the study period, particularly, public consultations (see Section 7.13). Local communities, within the research study, were caught in a ground hog day scenario of public consultation, relating to PCG configuration, PCG mergers and PCT status, which served to stall some local initiatives.

9.4 Use of Subgroups & the Position of the Lay Member

Again theoretical claims in relation to the art of distributions can be linked to observations of the structural development of PCGs. Foucault (1977b:141/142) identifies disciplinary methods, which enclose and partition the body providing a protected place of disciplinary monitoring, each individual has their own disciplinary space – a tactic that aids efficiency. The national survey, case studies and interviews identify that the functions of PCGs were partitioned and enclosed through the extensive use of subgroups (see Section 6.3.5, Table 8). Although used to aid efficiency (Foucault 1977b), case study evidence suggests the development of lateral invisibility (Foucault 1977b), where groups were aware of the overall aims and objectives of the organisation, however, were unaware of the work being done in other groups.

Therefore, function and activity is compartmentalised moving against public involvement as integrated and systematic. This led one lay member in Case Study B, to start rotating her membership in an attempt to increase the visibility of public involvement (see Section 7.12). Another aspect of the art of distribution focuses on the art of rank (Foucault 1977b:147), with an assignment of place that corresponds to the function of each individual and their value. In organising 'cells' 'places' and

'ranks' the disciplines create a complex space, which can be architectural, functional and hierarchical (Foucault 1977b:148). Again this can be linked to the partitioning of PCG work into subgroups or work streams (see Section 6.3.8), but also the rank and value placed on the lay member. Allocation to specific groups and functions within the organisation reveals lay representation predominantly in public involvement and health improvement (see Section 6.3.4, Table 7).

Further aspects of classification and distribution can be seen within the research. Analysis of reports (User and Public Involvement: A Review of Progress and Action produced by lay member in Case Study A, September 2000) showed the containment of the community participation groups' decision-making to areas that did not challenge corporate or professional structures (see Section 9.5 for further explanation).

9.5 Governmentality & Managerial Behaviour

The impact of governmentality can be seen with an example taken from Case Study A, which presented as an open, enthusiastic PCG, that actively encouraged involvement (see Section 7.2). The Community Participation Group was an initiative devised and instigated by the PCG Chief Executive and lay member in January 2000. The Terms of Reference and discussions at the first meeting (Source:field notes) revealed a vision of the group as a vehicle to initiate and evaluate public involvement. However, within less than a year its function and existence was openly questioned by both PCG personnel (from analysis of agenda items and minutes of meetings) and an external academic report, although, the reasons behind this ineffectiveness remained unanswered. It was clear from User and Public Involvement: A Review of Progress and Action produced by lay member in Case Study A (September 2000) that the group had failed to impact on the organisation and affect cultural change (see Box 35).

BOX 35

Lack of Subgroup Achievement

- Lack of impact in changing and improving services
- Lack of engagement with PCG staff in relation to public involvement agenda & contribution to future planning
- Lack of user and carer network
- Lack of engagement with other subgroups of the Board
- Lack of effective feedback mechanisms (User and Public Involvement: A Review of Progress and Action Plan, 2000)

However, throughout the existence of this group (2000 – 2002) aspects of governmentality and discipline affected its function and direction. PCGs not only had to deal with dominant discourses focusing on national frameworks, standards and targets (Joyce 2001) the organisations also had to address a centrally driven change agenda, which included a compulsory move to Trust status.

The group agenda was dominated by issues of government provenance rather than locally generated (see Appendix 23 – agenda examples) - a forthcoming merger (linked to PCT preparation), researchers attempting to access government funding for centrally prescribed research issues, preparation for PCT status, discussions relating to the National Plan and national involvement structures such as PALS and Patient Forums (see CPG Matrix, Section 7.3). The critics of the group failed to acknowledge the part played by PCG personnel in its management and its control over agenda items (constructed by the Partnership Development Manager and the Business Manager). The agendas tended to override the group's initial terms of reference and PCG management personnel failed to see their own role in the construction of group function that was dependent on the national agenda.

Primary Care Trusts also felt the impact of governmentality and the introduction of national involvement vehicles had hampered decision-making in relation to local involvement. As identified in Chapter Eight, a number of concerns were voiced regarding the pace of policy change and its impact on primary care organisations, this again highlights the realities of steering at a distance (Hughes and Griffiths 1999), with a dominant discourse focusing on modernisation overriding local organisational priorities (see Section 8.4.1).

> NED544: … there's such a huge agenda (yeah) erm that to some degree there's a feeling that we've lost the local perspective about it. The agendas are coming from government without giving us time to sort of really interpret it locally and make a difference

Other informants wondered how the changes would be operationalised.

> NED529: … it all sounded wonderful on paper, it was only when people began to consider how the heck we do it that it began to dawn on them that was not going to be that simple …

Chapter Eight discussions also identify the potential stalling of local involvement initiatives as PCT's awaited further guidance unwilling to anticipate government dictates.

> NED371: … we don't want to do something and then find its not what, you know, we've just wasted our time as it where

The above discussions show evidence of the effect of governmentality on organisational behaviour, which tended to emphasise docility, delaying local decision-making and maintaining the status quo. Hughes and Griffiths (1999:74) suggest that governmentality can identify a domain outside of government and seek to manage it without destroying its autonomy. This is made possible through agents who take forward the business of government in their self-directed activities in a variety of dispersed sites. Foucault (1977b:174), as discussed in Section 9.2, also identifies the role of supervisors, specialised and distinct from workers, an adequate description of NHS managers.

The case studies reflected specific organisational behaviour in relation to these central demands particularly in relation to PCT status and national involvement vehicles (see Section 7.6, Section 7.13), which Sheaff et al (2004) would describe as policy-compliant and docile. Most visible were managers' reactions, which were linked to

their 'right to manage' (Clarke 1998:196/197) key aspects of PCG operations, which included public involvement. Clarke (1998:195) provides a useful description of typical managerial behaviour incorporated within a managerialist mode of co-ordination (social organisational practices related to a set of complex rules or procedures). Clarke (1998:197) views managerialism both as an ideology 'centred on expanding the right to manage in the pursuit of greater efficiency in the achievement of organisational and social objectives' and as a process '… establishing managerial authority over corporate resources (material, human, symbolic) and decision making about them …' (Clarke 1998:198). Managerial behaviour can be linked to important concepts such as core business: -

'… the managerial attempt to define the focus of attention of the organisation – either externally-oriented in terms of competitive positioning, or as the internal management of 'waste and inefficiency'. Such specifications order the priorities of different potential calls on organisational resources and are formulated within the range of possibilities that are constructed by external or statutory requirements and internal organisational politics. Perhaps more important, the specification of core business legitimises withdrawal from previously undertaken activities that become redefined as 'inessential'…'

This mode of co-ordination can explain the behaviour of managers in relation to public consultation regarding PCT status and can also be linked to Foucault's (1977b) discussion on signalisation and its link to discipline. Foucault (1977b:164) identifies that efficiency requires a precise system of command, all activity of the disciplined individual must be punctuated and sustained by injunctions, orders must elicit the required behaviour, known as signalisation. It is important to perceive and react to the signal, bodies are therefore placed in a world of signals and each has an obligatory response. This can be interpreted in terms of central policy commands or signals and the resulting NHS managerial behaviour. Such responses are developed over time through corrective training or dressage (Foucault 1977b). Again dressage is linked to docility (Sheaff et al 2004) and relates to how people act within the work place, with institutions manipulating and modifying such behaviour over time via its use (Lynch 2004:133).

Aspects of managerial behaviour can be seen within data from this study – an important example was observed in Case Study A with the PCG management team developing a work stream for public involvement alongside the Community Participation Group (see Section 7.4), making the latter's function rather redundant. The new group was lead by a PCG Chief Executive and was managerially and professionally dominant, this group proceeded to develop a public involvement strategy unilaterally. A potential explanation is that public consultation and an involvement strategy had been redefined as an element of core business, an aspect which is essential as part of a successful bid for trust status and, therefore, a management priority. Here, the sidelining of the Community Participation Group is seen as legitimate (Clarke 1999). However, underlining this behaviour is governmentality and discipline with managers acting as agents for central directives, consciously or unconsciously, excluding potential challengers (Lukes 2005) and attempting to maintain the organisational status quo (Lynch 2004:133).

This suggests that a NHS organisation can regain professional and managerial control over identified key areas, which includes public involvement. Public consultation in relation to trust status had become an organisational priority (Clarke 1999) and also defined as an inappropriate area for active lay involvement, not suitable to rank and qualifications (Foucault 1977b). The ability to give and remove power may in part be due to the single status nature of lay members within primary care groups. As already stated, Hughes and Griffiths (1999:74) suggest that NHS systems and mechanisms influence behaviour across temporally and spatially dispersed sites and it was interesting to observe that the sidelining of lay members occurred in more than one PCG (see Section 8.1.10).

9.6 Recruitment as a Disciplinary Mechanism

The recruitment of lay members and non-executive directors can be linked to Foucault's (1977b) discussion on panopticism and its effects on social systems. As discussed in Section 9.2, authorities can use disciplinary mechanisms as a means of reinforcing or reorganising internal power mechanisms (Foucault 1977b:216). The recruitment system was based on egalitarian principles and an equal opportunity for lay participation was given in government guidance. HSC 139 (1998:11) stated that

the position was 'open to any member of the public' with the exception of general practitioners, nurses and NHS staff (see Section 4.4). However, the research study suggests the operation of a system of micro-power, which is non-egalitarian (Foucault 1977b:222) – a more informal recruitment system, where individuals already operating within established and acknowledged systems (e.g. CHC, voluntary organisations, local government) would have access to information regarding forthcoming positions – a potential systemic bias (Lukes 2005) (see Section 6.3.1).

> NED184: Erm and I just applied, like anybody else would, but obviously erm it was different because I obviously knew how we'd got to the point of becoming a Trust, which the others obviously don't know…'

For some the information was provided through established informal networks

> NED147: … so although I was on the erm a lay person on the Board erm I wasn't actually given that information in advance, it was at other meetings at, in other places that people said, now's the time to get your name on the list of er potential appointees erm so its certainly seemed to be those in a position to hear about it, heard about it …

At the time of research (1999 – 2001) governmentality continued to influence the recruitment of lay people, with continuing central control over the final decision-making on positions for non-executive directors via regional offices. Such recruitment issues also related to the composition of members of working groups and subgroups of PCGs (see Section 8.1.5). For example, the Community Participation Group membership, although fluid, was management-initiated (via Chief Executive and lay member) and was developed through established formal and informal networks. Analysis of group membership found little representation of harder to reach groups or those affected by social exclusion (see Section 7.6). This was indicative of other subgroups within the research such as those identified and discussed in Chapter Eight and the Public Participation Subgroup in Case Study B. The over reliance on established networks and inadequate profiling (see Section 7.6, Section 7.13) also had the potential to maintain an organisational invisibility to the majority of local constituents (Foucault 1977b).

The recruitment system could be seen as a disciplinary mechanism itself, used by established NHS organisations to maintaining docility, utility and the status quo. The lay profile shows an experienced professional membership (see Tables 1, 2, 3 & 4, Sections 6.1, 6.2). Typically an individual with a pre-existing knowledge of the health system, a person who could easily fit into the pre-existing structure and work

efficiently. An aspect of docility and utility perhaps can be seen by the internalisation of institutional and professional values and beliefs (Lukes 2005) by some lay members focusing on public perception. The public are described as apathetic and fickle, not wanting to get involved or who have axes to grind.

> LM163: It's difficult to say because the public are very fickle they are interested if it, if they feel its something connected with them, if its not, they feel connected with them, then they are not interested.
>
> LM235: Probably the main obstacle is knowing how to get it, involving people without involving, without over involving individuals with axes to grind, getting a broad spectrum of users and to some extent non users in terms of what they're looking for, and I think worth mentioning the fact that there always some health care professionals who know perfectly well what the public want without them having to be asked
>
> LM162: … I don't think the public are very interested yet,

Public disinterest is also used a reason for the lack of success of public involvement initiatives. There are instances of the use of sweeping statements to encapsulate public opinion and tend to support Clegg's (1989) description of the general public domain as chaotic

> LM529: … short of scandals, mass murders etc, the, the public aren't very interested in health except, in so far, if impinges on them and their nearest and dearest…
>
> LM529: … 95% of patients are quite happy with their doctors, their nurses, the treatment they get and there's a lot more grumbles about the hospitals for instance, I think that's properly natural because they're a more er spectacular
>
> Lay Member (2): … the public don't want to be too involved, they become involved and want to be involved when something happens to them or their family…'

Acceptance for the lay member was also linked to a non-threatening position and this perhaps reflects another element of docility, where threatening or challenging behaviour is seen as 'abnormal' and not socially acceptable (Foucault 1977b, Gutting 2005).

> LM529: … they didn't view me as an interloper, er I did talk to other lay members of other groups, where the relationship had been less happy, shall we say, and they were very much sidelined.
>
> LM200: I think the fact I've not affected them in any sort of way erm but erm I not erm I'm not an enemy shall we say, I think there are other outside bodies who they do dislike erm for example erm the Community Health Councils and some of them are very wary of them because they involved with helping patients with complaints …

LM162: … they wanted to hold me at arms length shall I say, they really weren't quite sure why I was there and it was (pause) I was an alien to them, erm therefore, I was very, very careful, very sensitive of their, I won't say mistrust, that's perhaps a little too strong but their erm apprehension …

Furthermore, the internalisation of abbreviations and medical knowledge was highlighted as a training need. One lay member, a lead in public involvement, had developed a 3,000-word glossary in relation to abbreviations (see Section 8.1.1).

9.7 The Invisibility of Public Involvement within PCG/Ts

The above discussion illustrates the marginalisation of the lay member within PCT consultation (Section 9.5). It also starts to identify themes of visibility and invisibility. Within this research the lay members position was open to change within the PCG/T structure. Observations and discussions with members from both case studies and Phase Three suggested the marginalisation of lay members (see Section 8.1.10). Failure to provide an adequate job description for the lay member had left some feeling at a disadvantage (see Section 8.2.1). The job description would have given the lay member a visible documented role, however, without a tangible physical example or a description of duties and responsibilities such individuals could be potentially left in a void. It can be seen from the discussions that, in some cases, this led to the questioning of the legitimacy of the role and informants talk about attempts to gain validity

LM411: … nobody quite knows why you're there (laughing) therefore, they don't really take you seriously, not that anybody was rude or anything else but you just felt completely, a lot of the time completely superfluous

LM297: No roles were actually offered to me, I can remember that, at one of meetings I don't know when it was … we certainly had a meeting where we whether we should set up subgroups for, you know, certain areas such as clinical governance, the health improvement programme, er this sort of thing, education and training and people virtually volunteered to do these er and be involved with them and then again, sort of, the chairman, obviously the GP was nodding at various people and we naturally put down for these but er it didn't seem as though there was any sort of idea as to, you know, what we ought actually to be doing and certainly there was no group set up for public involvement

There are incidents of health authorities being unsure of the role of lay member surfacing in examples of inadequate training even though the role is linked to leadership of public involvement in government policy (see DoH 1999a:11 'Patient

and public involvement in the new NHS) and again this undermines the visibility of lay people.

The research also identified the continuing invisibility of these new primary care structures to local constituents, fulfilling an important aspect of panopticism with NHS organisations maintaining a faceless gaze over their population (Foucault 1977b). The evidence from this research reflects a number of examples where information was either deliberately or inadvertently controlled resulting in restricted information to the public. For example, in Case Study B, a PCG leaflet was produced by the communications manager - on analysis its content was unremarkable and factual and its distribution was first discussed at subgroup level in November 1999. However, its distribution continued to be restricted by management and GPs throughout the two-year study.

Furthermore, documentation from a communications study day revealed that some board members saw no need to communicate with external stakeholders with the main focus for communication on PCG staff members (see Section 7.10). Similarly an Open Day celebrating the first year of the PCG was specifically aimed at NHS personnel rather than local constituents (see Section 7.9). Lack of public awareness can then be used as a self-fulfilling prophecy - it is very difficult not to be apathetic and disinterested when you are not even aware of the existence of such groups and Trusts. In contrast, analysis of the methods used by PCGs (see Section 8.1.6) identifies the organisations externalised disciplinary mechanisms and forms of disciplining (Foucault 1977b) e.g., moving out into local communities to give and receive information.

Certain forms of knowledge were again seen as legitimate with the GPs knowledge seen as particularly important. Some examples show little time is given to address different types of experience such as that held by the lay members themselves, again effecting visibility at board level (see Sections 8.2.2 and 8.2.4). This is reflected historically with the subjective construction (Foucault 1977b) of lay people emphasising what they are not and what they haven't got – namely they are not medical professionals and they do not possess medical knowledge (Hogg and Williamson 2001). This certainly reflects Foucault's assertion that power focuses on

such discrete subjectivities (Clegg 1989) and the lay members role has been defined under the conditions of long standing relationship with the medical profession. Here the 'truth' (Hogg and Wlliamson 2001) is linked to their lack of medical knowledge and areas of involvement are regulated using this truth.

> LM411: There was no opportunity for people to put forward their past experience and to gain credibility, I mean GPs all knew, and all know each other obviously and know what they are bringing because they are already a group but for new people coming in. It was for me a problem, for the er social services rep at that time. We, we found it quite difficult to get anybody to recognise the experience outside of GPs, primary care, was actually valid …

> LM351: …there was no real job description the other board members could see to help to understand because of my background in that I'd run the local council of voluntary service and I'd run a large local, a charity as well erm my network throughout the voluntary sector are very strong and we have a system locally of special interest forums through the different client groups as they all send me their minutes and I've got a good working knowledge of what the issues, not a detailed knowledge, but a working knowledge and certainly know who to talk to if more is needed.

This disregard for different forms of knowledge can be seen in the lack of direct participation of GPs in public involvement initiatives (see Sections 7.3, 7.9 & 8.1.5). Also in the accounts of GPs attempting to listen to users views, however, falling asleep instead (see Section 8.2.4). This seems to be a particular non-verbal communication, a discrete method of dismissing lay experience.

> LM351: … and we went, only half the GPs turned up and of the half who turned up the other half went to sleep and all of these very brave people, not brave coz they got a disability but brave because they were speaking out and wanted to share their, experience, told us about the services they provided as a voluntary organisation and what it is they needed and how they worked together and how they thought they could work with the PCG but it was quite embarrassing even my own GP went to sleep and er it was just appalling behaviour.

The discounting or lack of acknowledgement of skills and expertise again combine to impact on the visibility of lay involvement.

9.8 Resistance

Gordon (2002) identifies that Foucault was not only a philosopher but also an active campaigner and an advocate for reform with discussion regarding struggle and resistance evident within his work. Again, Watson (2000:68), in discussing Foucault's work, identifies that the 'micro-physics' of power suggests that there are countless

points of confrontation and instability and numerous possibilities for tactics and strategies of resistance. In discussing governmentality, Foucault (1982) suggested that resistance could be linked to a dissatisfaction in the way people were governed, indeed, he was writing in a time where he believed that government was in crisis. Foucault (1982:331) suggested that there could be strong resistance against the form of power that applies itself to everyday life, which categorises the individual, a form of power that makes individuals subjects, that subjugates. Struggles against subjection, exploitation and domination are interrelated and can be linked to the discussion on discipline in Section 9.2.

Foucault (1982:329) went on to advocate studying different forms of resistance that develop in response to different forms of power. Resistance, therefore, could act as a 'chemical catalyst' identifying power relations, locating their position, finding out their point of application and the methods used (Foucault 1982:329).

'… in order to understand what power relations are about, perhaps we should investigate the forms of resistance and attempts made to dissociate these relations' (Foucault 1982:329)

The research did identify areas of resistance, which included reactions to the traditional role of the non-executive director, the development of inclusive strategies and proactive local involvement initiatives. Aspects of subjection are discussed by Clegg (1989:151) identifying that through language a sense of self as 'distinct subjectivities' is gained and such subjectivity is constituted through 'discursive practices' and determined as the norm. This process is always subject to reproduction or transformation through discursive practices, which secure or refuse particular posited identities (Clegg 1989:151).

The transformation of identity can be seen as lay membership moved to non-executive directorship, unlike lay membership, these positions had a highly developed set of discursive practices. The role was strategic with a strong emphasis on probity (Williamson 1995, Lilley 2002, District Audit 2002). However, interviews with informants, explored in Chapter Eight, reflected a resistance to this new identity with attempts to re-define the role as active and hands-on, with direct involvement in

decision-making (see Section 8.3.2). Furthermore, non-executive directors had also developed strategies to regain access to what were perceived to be the decision-making arenas (see Section 8.3.3). This not only included attempts to re-define the role of non-executive director but also joint working and subcommittee membership as well as utilising authority and the lay majority (see Section 8.3.4). Such strategies can also be seen as a way of increasing their visibility within the organisation.

The success of increased visibility seems questionable - in discussing overall experiences with non-executive directors after six months within post there was still a perception that real power lay with the Executive Committee and that they continued to have little influence (see Section 8.4.3). Here, the perception focuses on the board being controlled by officers, in some cases, the two structures had not met

> NED273: … I felt that we were still being very much under the control of the officers and the exe directors, which disappointed me somewhat …

Interestingly, one patient participation group did present as particularly successful (Case Study A – see Section 7.3). This group had a positive and effective relationship with practice staff and GPs, strong leadership and developed local service at the practice. An explanation for the group's success potentially lies in its ability to remain relatively invisible to PCG management. The group was self-directing and self managing, making autonomous decisions with little support from PCG personnel. The circumstances of the group potentially protected it, to some extent, from disciplinary mechanisms and the generalised surveillance indicative with the faceless gaze of the PCG (Foucault 1977b).

Summary

This chapter has attempted to provide a distinct explanation for the evidence from this research study – identifying the effects of governmentality and disciplinary mechanisms on the development of public involvement in primary care organisations. Such organisations remained relatively invisible to their local constituents, surveying and monitoring the population, making health decisions with a selected few. Recruitment of lay representatives suggested a parallel micro-system of power (Foucault 1977b), which was potentially restrictive and inequitable. It also suggested

the manipulation of the lay identity – the lack of job description and the treatment of lay knowledge as inferior, sometimes resulted in the reduced visibility of the lay perspective and feelings of isolation. Furthermore, subgroup analysis showed definite lay and professional domains, with little lay visibility in key operational areas. As PCT status approached the lay identity was unilaterally and subtly re-negotiated, with public consultation re-emerging as a managerial/professional priority, again, leading to the reduced visibility of lay involvement. However, such invisibility could also prove advantageous with evidence of groups developing pro-actively beyond that panoptical gaze. There was also evidence of resistance with examples focusing on the re-definition of roles and the development of strategies to increase visibility and active involvement. The final chapter returns to the main findings of the study and continues to explore governmentality and discipline within the context of future developments in primary care and public involvement.

CHAPTER TEN

History Repeating

Introduction

The conclusions of this research study suggest that many areas relating to public involvement appear to be a case of history repeating. The concept of public involvement continues to be narrowly defined with a predominant focus on current service users, with little evidence of the incorporation of the wider general public or hard to reach groups. Over reliance on established voluntary networks and an unchanging demographic lay profile suggest difficulties with representation remain unresolved. Although some lay members suffered from a lack of detailed job description and inadequate training, all members developed a variety of roles, for some, stretching through to PCTs, with the majority describing their experience as rewarding and enjoyable. However, the majority of involvement initiatives continue to focus on information exchange rather than active participation, with emphasis on service responsiveness and quality. There was limited evidence of systematic and strategic development, with inadequate attention paid to the construction of an effective communications mechanism or the development of organisational capacity. Identified expertise, literature and research were not always utilised, with a bias towards experience rather than knowledge. Again evaluation remains at best superficial, but more often absent.

The explanatory phase of this research explored some of the reasons for the repetitive and limiting nature often associated with public involvement and the NHS. The main finding of the study is the effect of governmentality and disciplinary mechanisms was to severely constrain public involvement and it therefore failed to achieve its wide-ranging benefits. The use of national targets, standards, priorities and primary care directives have served as regulatory and surveillance mechanisms shaping and manipulating local reactions to involvement. Overall policy formation and implementation can be interpreted as a means of maintaining the status quo of established power interests within the system.

The conclusive remarks of the thesis return to the perspective of the researcher practitioner and its connection between critical analysis and the final chapter's

discussion and recommendations. The chapter reflects the belief that such analysis needs to stimulate pragmatic recommendations, which practitioners and managers could realistically utilise to move lay involvement forward. This stance is particularly influenced by my role as practitioner and the previous frustrations of attempting to turn critical academic analysis and findings into workable solutions. Therefore, the final chapter briefly explores research findings in relation to the continuing development of primary care, Third Way ideology and existing involvement structures. The discussion investigates the practicalities of challenging docility and provides concrete examples of innovative practice whilst re-stating the importance of evaluation.

10.1 Implications for Future Developments in Primary Care

The evolutionary process of primary care (Smith 2000) and the central modernising drive continues. Governmentality and disciplinary mechanisms have the potential to continue to negatively impact on local involvement, with organisational change linked to the impediment of local public involvement strategies (Audit Commission 2000). This is likely to persist with current plans for PCT mergers in 2006 and the further fragmentation of the service as PCTs relinquish their provider role (see Our health, our care, our say: a new direction for community services, DoH 2006). There is a danger that public involvement will be stuck in a Groundhog Day scenario of consultation surrounding operational and structural issues, issues with little direct value to local constituents. Such consultation does not facilitate genuine involvement (Christie 2000), indeed, the impact of public consultation on organisational decision-making proved very vague within this research. Larger primary care organisations also risk increased bureaucracy, corporate greyness and distancing from the local community (Audit Commission 2000, Shapiro 2000). Structural changes may also lead to failures in organisational memory, where personnel do not have the time or responsibility to take public involvement and related recommendations forward (Curtis et al 2004).

10.2 The Impact of the Third Way

Although this study agrees with Lynch's (2004) assertion that governmentality exists independently of political ideology, Third Way politics do seem to have acted as an enabling ideology for continuing domination. Fundamentally, the ideology consists of

a combination of marketisation and social justice, and can be seen itself as a way of maintaining the status quo (Pickard and Smith 2001). Beland et al (2003) identify the inherent difficulties in combining these elements. Combination leads to complex and ambivalent legislation with a strong emphasis on generality rather than specifics, this generality is evident in relation to public involvement in PCG/Ts, with a lack of detail relating to a number of essential areas. In these circumstances such directives create a policy vacuum (Sheaff 1999). Policy makers fill the vacuum by letting policy emerge, policymakers rely on implementers to invent detailed policy whilst implementing the broad initiatives (Sheaff 1999:259). However, this study identifies that implementers, via governmentality and disciplinary mechanisms, de-prioritised involvement or redefined it as consultation, with a strong emphasis on responsiveness and quality (see North et al 1999, Calnan and Gabe 2001, Milewa 2002b, Rowe and Shepherd 2002, Baggott 2005). The result was that democratic renewal was left unrealised (Rowe and Shepherd 2002). Furthermore, there are many examples of the government attempting to develop policy on the move, Anderson and Florin (2002) criticise examples of national high-speed exercises with results returning to the secrecy of government, such exercises leave people outside the system and can weaken local involvement. The persistent use of listening exercises, identified before, during and after this study could suggest a government with a limited vision not only of involvement but the future and nature of the NHS itself.

Furthermore, there is little evidence that citizenship and responsibility was part of policy implementation, as Baggott (2005:547) suggests

'… choice rather than voice is being prioritised as a mechanism of securing more responsive services', and there is 'a general under-conceptualisation of the relationship between consumerism and citizenship, a fault-line that seems to run through many of the Blair Governments' public service initiatives'.

Fawcett and South (2005) also identify the promotion of the consumer and to a lesser extent the citizens' voice in healthcare, but suggest that power of local communities remains unclear. The government has shown little interest in suggestions for strengthening public and patient involvement through democratisation (Baggott 2005). The evidence perhaps points to the social control or manipulation of the public

(Rowe and Shepherd 2002, Baggott 2005) and maintaining the status quo (Foucault 1978). Within this research study, there were few examples of public involvement incorporating citizen responsibility, whilst many authors advocate such citizenship with its emphasis on rights, responsibilities and an active collective role (Calnan and Gabe 2001, Crowley et al 2002, Sang 2003, Milewa 2004).

10.3 Public Involvement & Continuing Centralsim

The NHS Plan (2000) and developing health policy has at least increased the visibility of involvement vehicles with the development of PALS, PPI Forums and ICAS. However, evidence of governmentality and disciplinary mechanisms remain with implementation of these structures described as confused and disorganised (Baggott 2005). These vehicles lack resources and are inherently advisory and there remain continuing problems with democratic accountability with little evidence on the level of influence they inflict on service decision-making (Rowe and Bond 2003). Rather than vehicles for empowerment these structures can be seen as a blanket of surveillance permeating through the NHS, with the public acting as disciplinary agents.

Dowling et al (2004) also identify a continuing rigidity of targets which are involved with the present complicated process of modernisation, and also suggest, along with Pownall (2004) that PCTs operate as appointed government agents in relation to such targets. Again, as within Chapter Nine discussions, there are criticisms that national targets crowd out space of local autonomy and Strategic Health Authorities merely operate as 'outposts of the centre' - power devolved to local level is only the power to implement government policy (Pownall 2004:15). North and Werko (2002) also identify the continuing regulatory control of the NHS via performance indicators, standards, priorities and audit, with Shapiro (2004:12) critical of measurable accountability, which is viewed as at odds with professional work and he describes the NHS as 'risk adverse, punitive and highly disempowering'.

10.4 Challenging Docility

This research shows that lay members are not average members of the public and remained unrepresentative of their constituencies. They are highly professional self-motivated experienced individuals, with a quarter having worked at sometime for the

NHS. Although providing an unquestionable contribution, this research study suggests that disciplinary mechanisms impact on the recruitment system indicating a potential bias with the need to continually review the equity of the recruitment process. There is also some evidence to support Hogg and Williamson's (2001) view that lay members are not always public or patient orientated. Discussions in Chapter Eight and Nine suggested that some participants had taken on the beliefs and values indicative of the service – particularly pertinent are views relating to the use of proxy and the view of the public as apathetic and self-serving. This research agrees with recommendations from the document 'In the Public Interest, Developing a Strategy for Public Participation' NHS Executive/IHSM & NHS Confederation (1998) and Brotchie and Wann (1993) that training for lay members should be independent. The use of external providers could potentially reduce the internalisation of cultural values. Part of this training could include distinctions between the role of citizen and service user, developing and maintaining contacts with the local community and maintaining a citizen perspective (see Bradburn et al 1999, Brotchie and Wann 1993) however, whether such a role would be acceptable remains debatable.

As lay members, non-executive directors, PALS and PPIFs do not operate from an electoral basis the argument of lack of democratic credentials can still be persistently utilised by government and the NHS to restraint or discredit individual, group or organisational views regarding the health service. Two options seem immediately evident. The democratic deficit could have been addressed by the inclusion of elected representatives within the framework of NHS decision-making, aiding accountability and creating authority (Somerville 2005). Health policy shows only tentative steps in this direction, along with the local authority scrutinising committees, recent publications 'Our health, our care, our say: a new direction for community services' (DoH 2006) reveal suggestions that local councillors could act as community advocates. Alongside this are more traditional initiatives such as strengthening the ICAS, a review of the survey programme and a comprehensive complaints system across health and social care by 2009 (DoH 2006). Rowe and Bond (2003) also view election to Foundation Trust boards as a step forward. However, with the democratic deficit left relatively intact, another option is to address issues of representation and legitimacy through widening participation via innovative practice.

10.5 Fostering Innovation – Genuine Involvement

Literature continues to emphasis the need for radical organisational change in developing genuine involvement (Bond et al 2001, Pickin et al 2002, Rowe and Bond 2003) with Sang (2003) and Milewa et al (2002b) identifying profound cultural challenges for health organisations in the future. Such cultural challenges can be seen in a plethora of government publications (see the NHS Improvement Plan (2004), Creating a patient-led NHS (2005b), Commissioning a patient-led NHS (2005c)) emphasising patient choice, personalised care, public empowerment and a fundamental change in professional and patient/public relationships. Foucault (1977b) suggests that institutions hold on to disciplinary mechanisms due to fear of change and the lack of an alternative, again, it seems effective involvement requires the search for alternatives, with a review of innovative practice. Thornham and Nicholson (2002) suggest that StHAs could foster such innovation and change and resist the performance management culture. The emphasis still remains to identify and share examples of excellence within patient and public involvement, what Milewa et al (2002b) call innovations in citizenship.

This section briefly discusses examples of innovative practice that have the potential to lead to more pro-active initiatives. As Chapter Nine has highlighted power relations are central to public involvement and Pickin et al (2002) also suggest that understanding the relationship and power balance between local communities and statutory organisations is crucial for effective partnerships. The authors describe an innovative piece of research suggesting the use of a dynamic model, which identifies inter-relationships between potentially constraining factors and go on to suggest that a radical shift in organisational thinking and behaviour is needed. Refreshingly Pickin et al (2002:41) provide a model to identify the major difficulties relating to ineffective engagement and in its self provides a useful starting point for organisational learning. It also identifies capacity building needs, particularly important is to identify and reduce restraining factors. The authors suggest that organisations need to manage conflict more constructively and develop sophisticated skills and techniques for community engagement (Pickin et al 2002:41). Encouraging innovation and tackling risk aversion would aid a more participatory culture (Pickin et al 2002: 41).

Anderson et al (2006) researched two primary health care developments in Bristol and found that exceptional people, in strategic roles, holding a shared commitment and vision of involvement were needed, acting as a motivating force with the capability of developing partnerships. Unlike the traditional methods of public involvement identified with this research, the authors describe a number of innovative approaches based in the community, which increased local involvement these included video booths, use of creative art, competitions and open days (Anderson et al 2006). The research also highlighted the importance of community development workers in maintaining regular contact with local constituents.

Crowley et al (2002) describe an initiative in Newcastle upon Tyne focusing on community participation in decision-making. Again a community development worker was funded by a local PCG, making an annual round of visits to 84 community groups. Information from visits and an annual health conference determined health priorities for the next year. The community development worker took forward the action plan and progress was monitored by a steering committee of local residents. The research identified tangible results including a counselling service and family support and youth projects.

Fawcett and South (2005) advocate the concept of social entrepreneurship, mirroring observations from Harrison and Mort (1998). This research focused on four Bradford PCG/Ts and the development of a Community Involvement Team. Like Pickin et al (2002) the teams' remit focused on developing organisational capacity. As the PCGs developed into Trusts, team members were evenly distributed between the organisations. Fawcett and South (2005) identify that the team functioned as an accessible, flexible resource acting as a skills base and training source. An example such as this could have countered some of the problems experienced with Case Studies A & B, training needs could have been addressed and nullified problems of not using theoretical literature. Furthermore, the team did not fit into the organisational hierarchy as a consequence they continued to keep the involvement agenda on going. The authors also suggest that social entrepreneurship is an ideal model for periods of rapid policy change, an observation very relevant to the current status of primary care.

Our health, our care, our say: a new direction for community services (DoH 2006:158) admits that systematic engagement is not the norm and again provides case studies relating to good practice, advocating best practice and emphasising the role of the Patient and Public Resource Involvement Centre. The resource centre became operational in June 2006, led by a consortium. Another national vehicle is the National Primary and Care Trust Development group (NatPaCT), which has already published supporting documents such as 'Engaging now: PCTs working with their communities to improve services and cut health inequalities' (NatPaCT 2004). The NatPaCT also shows evidence of out sourcing to the Health Services Management Centre to support work focusing on leadership and partnerships, areas of work included Public and Patients as Partners in the Health and Social Care Programme. How national resource centres will fair against hands-on local support as identified by Fawcett and South (2005) remains to be seen.

In analysing these brief examples, it is clear that difficulties can be overcome by showing how centrally defined directives can be integrated within a local process instead of becoming an end in themselves (Brownill and McInvoy 2000). Part of this integration is to make an assessment of how these directives fit in with the organisations' vision. The vision should remain the fundamental basis in which to withstand and interpret such directives. However, as Anderson and Florin (2002) and Anderson et al (2006) suggest organisations need to be honest regarding the scope for change and influence inherent in such initiatives

10.6 Tackling Evaluation

It is little surprise that researched initiatives were poorly evaluated, if at all. Although, this theoretical discussion agrees with Anderson et al (2002:20) that public involvement is a messy business, evaluation still needs to be adequately addressed. Indeed, the authors provide a good example of a planning cycle for public involvement, which includes five key elements: -

- Development of a vision, articulated in policy
- Collaborative Development of Strategy
- Audit of Current Practice
- Development and support of a range of activities

- Monitoring, evaluation and feedback (Scottish Office cited by Anderson et al 2002:21)

As can be seen this cycle is unremarkable with many elements appearing in the literature review of Chapter Two and perhaps there should be more attention focused on why organisations don't use such expert literature or adequately evaluate their initiatives, which links with the work of Pickin et al (2002).

South et al (2005) perhaps go a step further than most literature on evaluation by developing and offering a self-assessment tool for community participation. Following a literature review and audit of resources, the authors developed a set of benchmarks for community involvement calling the tool 'Well Connected'. The tool was piloted in two PCGs. The research suggests that the tool facilitated an assessment of progress as well as identifying areas for improvement, the scoring system also identified whether the organisation was developing a strategic approach. Other authors such as Allsop and Taket (2003) continued with the use of Arnstein's conceptual framework.

Final Summary

This was a large-scale piece of work providing a critical analysis of public involvement in primary care with the provision of extensive evidence of the implementation of this policy directive. The study has provided a detailed empirical investigation, over a period of time, of the early development of PCGs and the implementation of public involvement within these new structures. Furthermore, it has documented and explored the experiences of lay people in relation to Primary Care Groups and Primary Care Trusts. The research evidence suggests that the 'public' in public involvement is scarce or invisible. Furthermore, the research identified the omission of public responsibility within a definition of involvement. In an atmosphere of rights and increasing litigation, there is little evidence of reciprocal responsibility and this could provide an area for future research. The repeated cycle of attempts on public involvement can be explained through a Foucauldian understanding of governmentality and discipline. The findings and conclusions of this study have raised further questions regarding the ideology, policy and implementation of public involvement in a health service that is primary care led. This suggests that

the continuing tracking of primary care development and related public involvement is important, along with the identification and exploration of innovative practices.

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APPENDIX ONE
Manuals & Toolkits
(Listing & Analysis)

The Service First Unit (1998) 'How to consult your users' provides practical advice on consultation. The document assists the user by linking types of consumer with different methodology, a similar approach taken by McIver (1991) although her work focused more strongly on under represented groups. It is a substantial document, with the main body of the text dedicated to a review of methods associated with public involvement, for each of these – there is brief but clear method descriptions, as with many of manuals reviewed it provides methodological advantages and disadvantages, adding to this a cost evaluation combined with real life examples, contact names and numbers – although not all examples relate to health services.

The text also provides a visual display of all methods and a simple tick system is employed to evaluate each method in relation to cost, information exchange, representative views, quantitative and qualitative issues as well as special group views, which easily assists the user in their assessment of available methodology. The document also supplies explicit sections and suggestions on evaluating public involvement initiatives, which are often absent from many of the manuals. However, there is no advice on an integrated or mixed method approach and the document falls short of a strategic perspective, furthermore, although it identifies key elements relating to the evaluation to public involvement initiatives, there is too strong an emphasis on consultation methods rather than participation.

Martin and Hobbs (1992) cited in Martin and Evans (1992) 'A Framework for Public Involvement' are one of the few authors to identify the need for research and analytical skills, urging a progression from the use of descriptive methods in relation to public involvement. Gurney (1995) gives an in-depth critical review of methods utilizing three different databases, each method is described and a piece of research is taken as an example identifying who and how the public were involved, however like Service First Unit (1998), there is little to assist with strategic development, the only mixed method approach reviewed in any detail is the Oregon Experiment, which had inherent methodological difficulties (see Chapter Three).

Barker et al (1999) 'Reference Manual for Public Involvement' employs checklist tactics, however, it provides some information on evaluation and again gives a description and brief assessment of methods, which is more comprehensive than the 'Public Engagement Toolkit'. It differs from many manuals by linking levels of participation with different methods, the reader, therefore, is able to assess the level of participation indicative in each method (see Nine Zones of Participation, Barker et al 1999:14/15). Similarly, Kelson (1997) in 'User Involvement: A Guide to Developing Effective User Involvement Strategies in the NHS' also identifies different levels of involvement and provides checklists, however, they are designed to provide useful templates in development of a number of initiatives e.g., organizational issues, individual initiatives, steering groups. Beresford and Croft (1993) in 'A Framework for Evaluating Citizen Involvement in Agencies and Services' provide an essential text in understanding the underpinning values related to involvement, which includes issues of access, advocacy, support, training and finance. Although potentially useful in developing an overarching strategy, it is a complex and organizationally challenging text.

The document 'Patient and public involvement in the new NHS' (DoH 1999) identifies that public involvement forms part of the department's guiding principles and is part of management training, furthermore, there are diagrammatical representations of the integration of public involvement within the NHS structure. Throughout the report there is the presentation of good practice at health authority, PCG/general practice level, however, the examples are limited. Out of the 10 examples given, only five directly involved users within their approach, although contact names and numbers are given. Perhaps one of the most important aspects of the document for PCGs is in Annex C, which provides a framework to assist PCGs, and other NHS bodies, assess progress on involvement.

Box 3
Public Involvement Framework

Establishing a baseline
Record of activity involving users and the public
Resources allocated for user and public involvement
Availability of information relating to user and public involvement
Developing a strategy

Written plan for the systematic involvement of users and the public
Action plan with specific and realistic targets
Integration with organization's other strategies

Whole organisation approach

Clear statement of organization's commitment to user and public involvement
User and public involvement strategy and action plan incorporated into organizational and individual objectives
Training and education for all individuals on effective user and public involvement

Communications

A clear communications plan, explicit in terms of the organization's and individuals' responsibilities for communication with users and the public
Mechanisms for ensuring communication and awareness of user and public involvement activities within the organization
Mechanisms for ensuring 'two-way' communications with users and the public – active seeking of user and public views and giving feedback on findings and action taken

Nurturing 'champions'

Designated senior individual to oversee user and public involvement strategy
Designated individual to coordinate user and public involvement activities

Partnership with others

Contacts with other NHS organizations, professionals and managers to encourage user and public involvement across organization boundaries
Sharing information about user and public views with other NHS organizations (but not so to breach confidentiality)
Contacts with local user, community and voluntary groups about organization's role and activities

Inter-agency approach

Contacts with local authorities, social service departments and voluntary sector care agencies
Sharing of information about user and public views with other agencies (but not so as to breach confidentiality)

Evaluating progress

Assessment of whether user and public involvement activities achieved their stated aims
User, public, staff feedback on involvement activities
Were findings from user and public involvement acted on? (DoH 1999:26/27)

The sections are brief and not detailed enough to give any substantive support, however, it identifies important and essential elements when developing a public involvement strategy and has the potential to be used a template for individual Primary Care Groups.

The NHS Executive/ISHM and NHS Confederation (1998) report 'In the Public Interest' also makes an attempt at an overall strategic approach, identifying four different models for public participation within such an approach. The document also provides more detail examples of good practice and contacts from a variety of sources. The four highlighted models are: -

Box 4

Public Involvement Models

Model 1: Direct Participation of Users

Engaging user and voluntary groups in decision-making at local and national levels and building partnerships at the individual level between clinician and patient

Model 2: Informed Views of Citizens

Developing opportunities to engage with the informed views and experiences of citizens about health and health services

Model 3: Community Development

Mobilising communities to become participants in both defining problems and developing solutions to health and health service issues

Model 4: Local Scrutiny and Accountability

Developing more effective systems for ensuring public scrutiny and public accountability at both a local and national level.

The document gives limited examples of the types of approaches to use within each model, however, there are suggestions on when such models could and should not be used. The examples of uses for Model 2 are a little limited and the document does not really develop public accountability suggestions as well as it might. However, the importance of a multi-method approach is highlighted, with all four models having the potential to be drawn into the planning of a public involvement strategy.

The Public Engagement Toolkit (NHS Executive Northern and Yorkshire, 1999) is a document that is specific to primary care groups. It highlights different public involvement methods, again employing the tactic of brief description, stating advantages and disadvantages, only 16 methods of involvement are discussed, therefore, it does not offer a comprehensive guide. However, the toolkit addresses planning of involvement dividing the document into sections on motive, methods, and outcome. Motive includes auditing of resources; backward planning technique, the development of timescales, and addresses issues such as involving hard-to-reach groups and minority ethnic groups,

unlike many of the manuals it incorporates ethical and legal concerns relating to involvement initiatives.

As with Sykes et al (1993), Martin and Hobbs (1992) in Martin and Evans (1992) the document contains a strong focus on the research process and methods, although brief and simplistic. However, the important issue of feedback is included, identifying the need for data analysis, report writing, keeping the public informed as well as advice on possible feedback mechanisms. A strength of the toolkit is its use of appendices, which offers additional information relating important issues such as proforma for auditing resources, mapping public engagement initiatives, setting up general practice patient group, leaflet design, research development, all of which could be of practical assistance to PCGs. However, other appendixes on rapid appraisal and research design are too simplistic and underestimate the need for expertise.

It also provides a 'framework of action: constituents of a programme of public engagement'.

Box 5

Public Engagement Programme

- A process that is systematic and demonstrates the continuous involvement of users and the public
- A means of demonstrating to the public and relevant agencies, how the public has been involved
- A mechanism for feeding back to users and the public the outcome of their involvement
- An inherent process of continuous evaluation of the system(s) employed to achieve the above

(NHS Executive Northern and Yorkshire, 1999:12)

This reiterative of government policy, with no development or specific information given in relation to what might be meant by systematic process or inherent process of evaluation, the 'means' and 'mechanism' also are not elaborated. Inherent difficulties and issues, which directly impinge of public involvement, such as finite budgets, national targets, social, political histories are listed but are not addressed. There is no guidance given regarding incorporating a multi-method approach or developing an integrated strategy, it indeed treats public engagement as a series of discrete research projects.

Two specific, but disappointing texts are represented within 'The PCG Toolkit, a workbook for the health service and primary care team' (Lilley 1999) and 'The PCG Development Guide' (Wilson, 1999). Lilley (1999) provides a dedicated chapter to public involvement, like the 'Public Engagement Toolkit' it provides a brief description on a number of methods, the majority have a limited remit focusing on information dissemination and exchange, with strong emphasis on the public meeting, complaints and handling the media. The PCG Development Guide (Wilson, 1999) contains two chapters, which have direct relevance to public involvement – communication and involving stakeholders. Although it identifies the importance of developing a communications strategy with the success linked to quality relationships, it does not express ways of evaluating its level of effectiveness. Although Rowson (1999:154) identifies different levels of participation, it merely reiterates health policy, providing only descriptive accounts of involvement methods and offers little practical support.

A more integrated approach is attempted by the Health Quality Standards (HQS) published by Kings Fund (1999). These standards focus specifically on PCGs, analysis of standards and criteria suggests that a comprehensive approach to public involvement is required if they are to be achieved. Four main standards are identified within the document relating to: - PCG organization, clinical governance, PCG functioning and development to higher levels, many of the criteria within the standards identify aspects of public involvement e.g., the HimP should involve representatives of patients/carers and the local population, determination of local priorities should involve the local population, users and carers and voluntary organizations.

Again many of the criteria reiterate government guidance and act rather like a checklist, within these standards limited methods of public involvement are listed, however, there are no suggestions how these methods could be integrated within the criteria.

Furthermore, the levels of public involvement identified fall short of a definition of participation. Within the four standards are 116 separate criteria, how realistic the fulfilment of such criteria are in terms of motivation, time and resources has to be

questioned. However, the standards do acknowledge the importance of public involvement in a wide range of areas and the publication reflects one of the few attempts to relate specific standards to public involvement issues and could provide a supportive framework for evaluation.

APPENDIX TWO
Research Proposal

Jane Spink – Research Project

The Research Question

The research proposal focuses on public involvement in Primary Care Groups [PCGs]. The research question is stated as **'How is public involvement defined and operationalised within primary care groups?'** Particular research objectives within the area of research are: -

1. To provide a demographic profile of lay members serving as members on the governing boards of PCGs
2. To document and analyse the experiences of lay members on the governing boards of PCGs
3. To explore the developing role of the lay member in relation to the functions of the PCG i.e., health improvement, service development and commissioning
4. To explore different attitudes to the concept of public involvement utilising professional and lay perspectives
5. To identify specific methods of public involvement initiated by PCG governing boards
6. To identify effective strategies for public involvement in relation to the functions of the PCG

Data Collection Tools

The research strategy utilises both quantitative and qualitative approaches in addressing the research question and its objectives, the following research tools are incorporated into the research design: -

1. Questionnaire – sent to all lay members on PCG governing boards across England [481], data collection continues [60% so far returned]. Areas addressed on questionnaire were: - age, ethnicity, gender, occupation, social class, selection process, role development, role allocation, areas of development in relation to the functions of the PCG, training for role, This will address Objectives 1 & 3

2. Semi-structured interviews – to be conducted with lay members in May/June 2000, 20 – 30 interviewees recruited nationally for in-depth interview. I am hoping that this will include lay members on PCT's. This will address Objectives 2, 5 and 6

3. Case Study – 2 studies have been incorporated into the research study – [redacted] PCG and [redacted] PCG – this part of the study involves observation of the development and implementation of a public involvement strategy over 18-month period from October 1999 to April 2001. This will address Objectives 2, 3, 4 5, 6.

What I have to offer

Access to my research findings
Access to other national and/or local studies within the area of public involvement.

APPENDIX THREE
Questionnaire – National Survey

Primary Care Group/Lay Member Profile Questionnaire

Please answer the questions either by written comment or by ticking the appropriate box. This questionnaire is anonymous.

These questions focus on your role as a lay member

1. How did you first become aware of the position of lay member?

Local press ☐ National press ☐
Told of vacancy by colleague ☐ General enquiry ☐
Other route, please state
.....
.....

2. Were you formally interviewed for the position?

Yes ☐ No ☐

Further comments
.....
.....
.....

3. Were any members of the public involved with your selection as a lay member?

Yes ☐ No ☐

Further comments
.....
.....
.....

4. Have you developed any specific roles and responsibilities within your capacity as lay member?

Yes ☐ No ☐

If **yes**, please highlight roles and responsibilities

.....
.....
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.....
.....
.....

5. Within your role as a lay member, are you a member of any subgroups/special interest groups, which relate to the work of the Primary Care Group?

[E.g., commissioning subgroup, resource allocation, communications, public relations, health improvement programme, prescribing, information technology]

Yes ☐ No ☐

If yes, please state the focus or title of group and, briefly, describe your role within the group [additional spaces are available if you are a member of more than one group]

Group 1

.....

Your role

.....

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Group 2

.....

Your role

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Group 3

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Your role

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Any other groups

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Your role

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6. Have you received any training to support your developing role as lay member?

Yes ☐ No ☐

Further comments

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.....

.....

7. How would you describe your role development?

Roles were allocated to you ☐
You volunteered for roles ☐

Further comment
.....
.....
.....

8. Please state the level that your PCG is operating at: -

Level 1 ☐ Level 2 ☐ Level 3 ☐ Level 4 ☐

If there is to be a change in level after April 2000 please state.....

9. Which type of area would best describe the locality of your PCG? You may tick more than one box if necessary.

City ☐ Suburban ☐ Semi-rural ☐ Rural ☐

Personal Profile

The following questions focus on some brief personal and professional/occupational details. Such information is seen as important in developing a profile of lay people who are actively involved in primary care and its completion would be appreciated.

10. Your age – please tick the appropriate box in the age range below:

18 – 30 ☐ 31 – 40 ☐ 41 – 50 ☐ 51 – 60 ☐ 61 – 70 ☐ 71 +☐

11. Your gender – please tick the appropriate box below: -

Male ☐ Female ☐

12. Your ethnic origin – please describe your ethnic background by ticking one of the boxes below: -

Black – British ☐ Black – African ☐
Black – Caribbean ☐ Black – Other ☐

Chinese ☐

Indian ☐ Pakistani ☐
Bangladeshi ☐ Asian – Other ☐

White – British ☐ White – other European ☐
White – other ☐
Other ethnic group, please state .....

Occupational Profile

The following questions relate to activities outside your role as a member on the Primary Care Group [PCG] governing board

13. Have you a paid occupation?

Yes ☐ No ☐

If **yes**, please answer Questions 14,15 & 16, if **no** please go to Question 17

14. Please state your occupation and job title

.....

15. Please state the nature of your employing organization

.....

.....

16. Do you work full-time or part-time?

Full-time ☐ Part-time ☐

17. If you are retired or not in paid employment, please state your last paid occupation and employing organization

.....

.....

18. Have you ever been employed by the National Health Service

Yes ☐ No ☐

19. Would you be willing to be involved in short interview [either telephone or face to face] regarding your role and experiences as a lay member?

Yes ☐ No ☐

If **yes**, please state your name, address and contact number below

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.....

20. Any further comments

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Thank you for your participation in this questionnaire

APPENDIX FOUR
Pilot Questionnaires

QUESTIONNAIRE

Please answer the questions by either writing a reply or ticking an appropriate box. This questionnaire is anonymous.

Personal profile

1. Age – please tick the appropriate box in the age range below:

18 – 30
31 – 40
41 – 50
51 – 60
61 – 70
71 +

2. Gender – please tick the appropriate box below: -

Male
Female

3. Ethnic Origin – please describe your ethnic background by ticking one of the boxes below: -

Black – British
Black – African
Black – Caribbean
Black – Other

Chinese

Indian
Pakistani
Bangladeshi
Asian – Other

White – British
White – other European
White – other

Other ethnic group, please state .....

Occupational Profile

Questions 4 to 8 relate to activities outside your role as a member on the Primary Care Group [PCG] governing board

4. Have you a paid occupation?

Yes
No
If yes, please answer Questions 5,6 & 7, if no please go to Question 8

Occupation profile continued

5. Please state your occupation and job title

.....

.....

6. Please state the nature of your employing organisation

.....

.....

7. Do you work full-time or part-time?

Full-time
Part-time

8. If you are retired or not in paid employment, please state your last paid occupation and employing organisation

.....

.....

Role as lay member

4. At what level is your PCG operating at?

Level 1 Level 2 Level 3 Level 4

5. Which type of area would best describe the locality of your PCG?

Inner City
Suburban
Semi-rural
Rural

9. How did you first become aware of the position of lay member?

Local press
National press
Told of vacancy by colleague
Other, please state .....

10. Were you formally interviewed for the position?

Yes
No

Further comments

.....

.....

.....

.....

11. Were any members of the public involved with your selection as a lay member?

Yes
No

Further comments

.....
.....
.....

12. Have you developed any specific roles and responsibilities within your capacity as lay member

Yes
No

If **yes**, please highlight roles and responsibilities

.....
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13. Within your role as a lay member, are you a member of any subgroups/special interest groups, which relate to the work of the Primary Care Group?
[E.g., commissioning subgroup, resource allocation, communications, public relations, health improvement]

Yes
No

If yes, please state focus or title of group and, briefly, describe your role within the group [additional spaces are available if you are a member of more than one group]

Group 1
.....

Your role

.....

.....

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.....

.....

Group 2

.....

Your role

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Group 3

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Your role

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.....

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Any other groups

.....

Your role

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.....

14. Would you be willing to be involved in a 20-minute interview [either telephone or face to face] regarding your role and experiences as a lay member?

Yes
No

If yes, please state your name, address and contact number below

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15. Any further comments

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.....

Thank you for your participation in this questionnaire

QUESTIONNAIRE

Please answer the questions by either writing a reply or ticking an appropriate box. This questionnaire is anonymous.

Personal profile

1. Age – please tick the appropriate box in the age range below:

18 – 30 ☐
31 – 40 ☐
41 – 50 ☐
51 – 60 ☐
61 – 70 ☐
71 + ☐

2. Gender – please tick the appropriate box below: -

Male ☐
Female ☐

3. Ethnic Origin – please describe your ethnic background by ticking one of the boxes below: -

Black – British ☐
Black – African ☐
Black – Caribbean ☐
Black – Other ☐

Chinese ☐

Indian ☐
Pakistani ☐
Bangladeshi ☐
Asian – Other ☐

White – British ☐
White – other European ☐
White – other ☐

Other ethnic group, please state..

Occupational Profile

Questions 4 to 8 relate to activities outside your role as a member on the Primary Care Group [PCG] governing board

4. Have you a paid occupation?

Yes ☐
No ☐

If yes, please answer Questions 5,6 & 7, if no please go to Question 8

5. Please state your occupation and job title

.....
.....

6. Please state the nature of your employing organisation

.....
.....

7. Do you work full-time or part-time?

Full-time ☐
Part-time ☐

8. If you are retired or not in paid employment, please state your last paid occupation and employing organisation

.....
.....

Role as lay member

9. How did you first become aware of the position of lay member?

Local press ☐
National press ☐
Told of vacancy by colleague ☐
Other, please state .....

10. Were you formally interviewed for the position?

Yes ☐
No ☐

Further comments

.....
.....
.....
.....

11. Were any members of the public involved with your selection as a lay member?

Yes ☐
No ☐

Further comments
.....
.....
.....

12. Have you developed any specific roles and responsibilities within your capacity as lay member

Yes ☐
No ☐

If **yes**, please highlight roles and responsibilities
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13. How would you describe your level of involvement as a lay member in the following areas: -

a. The Health Improvement Programme

Regularly Involved	Occasionally Involved	Minimal Involvement	Not Involved
☐	☐	☐	☐

Please give details/further comments
.....
.....
.....
.....

b. Specific Public Involvement Initiatives/Public Relations [e.g. patient focus groups, public involvement strategy, carers groups]

Regularly Involved	Occasionally Involved	Minimal Involvement	Not Involved
☐	☐	☐	☐

Please give details/further comments
.....
.....

c. Prescribing

Regularly Involved	Occasionally Involved	Minimal Involvement	Not Involved
☐	☐	☐	☐

Please give details/further comments

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d. Commissioning of services

Regularly Involved	Occasionally Involved	Minimal Involvement	Not Involved
☐	☐	☐	☐

Please give details/further comments

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e. Primary care development

Regularly Involved	Occasionally Involved	Minimal Involvement	Not Involved
☐	☐	☐	☐

Please give details

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f. Administration and Finance

Regularly Involved	Occasionally Involved	Minimal Involvement	Not Involved
☐	☐	☐	☐

Please give details/further comments

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.....

g. Clinical Governance

Regularly Involved	Occasionally Involved	Minimal Involvement	Not Involved
☐	☐	☐	☐

Please give details/further comments

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h. Information Management and Technology

Regularly Involved	Occasionally Involved	Minimal Involvement	Not Involved
☐	☐	☐	☐

Please give details/further comments

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.....

14. Would you be willing to be involved in a 20-minute interview [either telephone or face to face] regarding your role and experiences as a lay member?

Yes ☐
No ☐

If yes, please state your name, address and contact number below

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Any further comments

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Thank you for your participation in this questionnaire

APPENDIX FIVE
Covering Letter 1

Covering letter

Dear

I am a researcher at the Centre for Research In Primary Healthcare, Buckinghamshire Chilterns University College and my work focuses on public involvement within Primary Care Groups. At present, I am developing a profile of lay members and exploring their role as members of the governing board.

I should be grateful if you would help with this profile development by completing the brief questionnaire enclosed. This should take no more than 15 minutes of your time. The questionnaire is anonymous and thus no individual will be identified in any report or thesis. Please use the stamped addressed envelope for the return of the questionnaire.

The data collected will provide a greater insight into public representatives within the new organizational structures of the NHS and their developing role in primary care. If there are any further questions or enquiries please do not hesitate to contact me on the above telephone number, extension 2223 or if more convenient on E-mail jane.spink@btinternet.com or my home telephone no: - 01737 352410 between 8.00 p.m. and 10 p.m.

Yours sincerely

Jane Spink
RGN, Cert DN, BSc [Social Sciences], BSc[Hons][Nursing], MAEd[Open]

APPENDIX SIX
Covering Letter 2

Buckinghamshire Chilterns
UNIVERSITY COLLEGE

Buckinghamshire Chilterns
University College
Chalfont Campus
Newland Park, Gorelands Lane
Chalfont St Giles
Buckinghamshire HP8 4AD

Telephone: 01494 522141
Facsimile: 01494 871954

Faculty of Health Studies
Dean: Jean Powell
Faculty Fax: 01494 603182

27th March 2000

Dear

I am a researcher at the Centre for Research in Primary Healthcare, Buckinghamshire Chilterns University College and my work focuses on public involvement within Primary Care Groups. At present, I am developing a profile of lay members and exploring their role as members of the governing board.

I should be grateful if you would help with this profile development by completing the brief questionnaire enclosed. This should take no more than 15 minutes of your time. The questionnaire is anonymous and thus no individual will be identified in any report or thesis. Please use the stamped addressed envelope for the return of the questionnaire.

I am aware that there are various research projects associated with public involvement and that you may have already been approached for information, however, I still feel that developing a **national** profile of lay members and their contribution to primary health care is an important area of research. I would, therefore, appreciate your participation in my research study.

For further discussion, questions or enquiries please do not hesitate to contact me on the above telephone number, extension 2223 or if more convenient on E-mail jane.spink@btinternet.com or my home telephone no: - 01737 352410 between 8.00 p.m. and 10 p.m.

Yours sincerely

Jane Spink
RGN, Cert DN, BSc [Social Sciences], BSc[Hons][Nursing], MAEd[Open]

APPENDIX SEVEN
Interview Schedule

INTERVIEW SCHEDULE

LAY MEMBER ROLE

1.Please state appointment date as a lay member……

2. Have you received training your role as lay member?

Yes ☐

No ☐ **if no go to 6**

Comments……

……

……

……

3. What training sessions have you found to be particularly beneficial to your role?

……

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……

……

4. Did any training session, to your knowledge, focus specifically on public involvement methodology? E.g., different methods available, planning and developing initiatives

Yes ☐ No ☐

If yes, expand

……

……

……

……

……

5. How would you describe the quality of your training?

Excellent ☐ Good ☐ Adequate ☐ Poor ☐ Inadequate ☐

6. What training would have been useful to assist your role?

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7. Reflecting on your experience, how would you define the role of the lay member?

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8. How would you describe you overall experience as a lay member within the PCG?

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LEAD/CHAIR PUBLIC INVOLVEMENT

9. Could you briefly describe the events that led to your appointment as lead/chair?

.....

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.....

10. Were you involved in the development of the public involvement strategy?

Yes ☐ No ☐

If yes, explore experience of strategic planning. If no, identify who was involved.

.....

.....

.....

.....

.....

11. How many permanent members are there in the public involvement subgroup?

☐

12. Will you identify the main members of the subgroup?

Board members		**Local government**	
Nurse		Councillor	
GP		Other	
Non-executive			
Chief executive		**Voluntary agencies**	
Chair		CVS	
LA rep		CHC	
No board members		Other	
Other PCG			
HA staff		**Local Authority**	
		Social worker	
		Community Development Worker	
Others identified		**NHS Trust**	
PPG rep		**User group rep**	

13. Could you identify the methods used to involve the public?

Public meeting	Citizen`s panel
Focus Groups	Citizen's jury
Meetings with carers and user groups	Health panels
Survey/questionnaire	Local forum
Open surgeries	Conferences
Exhibitions	Open Space
Seminars/workshops	Others identified
Radio/live phone-ins	The Press
Patient participation groups	Subgroup of PCG
Newsletter	CHC [co-opted board member]
Rapid Appraisal	Website
Community development	Team syntegrity

14. Which methods do you think have been the most effective?

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.....

.....

15. Were any of these methods formally evaluated?

Yes ☐ No ☐

If yes, explore

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.....

.....

.....

.....

16. Has there been a specific budget allocated for public involvement initiatives?

Yes ☐ No ☐

Comments.....

.....

.....

.....

.....

17. Has anyone being specifically employed to develop public involvement within the PCG? [E.g., public involvement facilitator, outside consultant]

Yes ☐ No ☐

If yes, explore, if no check for short contract work.....

.....

.....

.....

18. In your opinion what have been the main successes for the PCG in relation to public involvement?

.....

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.....

.....

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19. What have been the main difficulties/obstacles in relation to public involvement for the PCG?

.....

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PCT STATUS

20. When has the PCG applied for PCT status?

April 2001 ☐ April 2002 ☐

April 2003 ☐ April 2004 ☐

Not known ☐ Already Trust ……..

21. Will the PCG have a merger before this takes place?

Yes ☐ No ☐

Unsure ☐ Potentially ☐

Already taken place ☐

22. Has any public consultation taken place?

Yes ☐ No ☐ **if no move to 25**

Comments……

……

……

……

……

23. Have you, as lay member, been involved with public consultation in relation to PCT status?

Yes ☐ No ☐

If yes, explore [check if active]

……

……

……

……

……

24. Can you identify the methods used for public consultation?

Public consultation	
Public meetings	Subgroup
Focus groups	Meetings with voluntary agencies
Exhibitions	Meetings with CHC
Conferences	Other methods identified

.

25. Will you be staying on as non-executive/chair when the PCG becomes a Trust?

Yes ☐ No ☐ Unsure ☐

Explore.....

.....

.....

.....

26. Have you any comments on the appointment system for non-executives? if not already identified in Q25

.....

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27. Have you any comments on PCT governance, the structure of the new Trust? if not already identified in Q25 & Q26

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.....

PREVIOUS EXPERIENCE

28. Have you previously held a position as a lay member?

Yes ☐ No ☐

If yes, specify

.....

29. Have you previously held a position as a non-executive?

Yes ☐ No ☐

If yes, specify

.....

30. Have you previously worked in the voluntary sector?

Yes ☐ No ☐

If yes, identify client group or nature of work

.....

31. Have you been a member of the CHC?

Yes ☐ No ☐

32. Have you had previous experience as a chair/lead?

Yes ☐ No ☐

If yes, please specify

.....

33. Have you been involved in public involvement initiatives before this present role?

Yes ☐ No ☐

If yes, specify

.....

.....

.....

34. How would you describe your knowledge of public involvement methods before this present role?

.....

.....

.....

PERSONAL & COMMENTS

35. Are you registered as disabled?

Yes ☐ No ☐

36. Are there any important issues that, you feel, the questionnaire has not addressed?

.....

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.....

.....

37. Have you any further comments to make?

.....

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.....

.....

Thank you for participating

APPENDIX EIGHT
Covering Letter 3

Covering Letter

Thank you for agreeing to be interviewed for this research project. As you are aware, I am a researcher at Buckinghamshire Chilterns University College, in the Centre for Primary Care Research. The project focuses on the development of public involvement within Primary Care Groups. As a researcher I am particularly interested in the role of the lay member and you have already kindly completed a questionnaire. The questionnaire has highlighted that many respondents were leading on public involvement and it is this area that I wish to explore further, as well as, your experiences as lay member. One of the aims of the research is to make recommendations on how to effectively recruit and support lay members who take on similar roles within NHS organisations in the future.

The interview focuses in four areas; experiences as a lay member, your role as lead/chair in public involvement, previous voluntary sector experience and issues relating to disability [an area neglected within the questionnaire]. I have enclosed a more detailed list of topic areas for you to read before the interview. The interview should last approximately 30 minutes.

The interview and data collected is confidential and anonymous. I would like, however, to tape the interview. This will ensure that the interview remains relatively short, as I will not have to make notes during our conversation. The interview will then be transcribed and analysed. However, if you do not wish for a taped interview, I will make notes as an alternative, although this may lengthen the interview. I would like permission to be able to use appropriate remarks within my thesis and these may also appear in research publications, this will not take place without your permission and they will be anonymous.

I will be contacting you within the next few days to arrange a suitable date and time for interview. Please do not hesitate to contact me if you wish further discussion or to clarify any points. You can contact me by telephone: 01737 352410 or E-mail: jane.spink@btinternet.com

Yours sincerely

Jane Spink

APPENDIX NINE
Original Research Proposal

RESEARCH PROPOSAL

Research Question

This research proposal focuses on public involvement in the recently formed Primary Care Groups [PCGs]. The research question is stated as **'How is public involvement defined and operationalised within primary care groups?'** Particular research objectives within the area of research are: -

- To provide a demographic profile of lay members
- To document and analyse the experiences of lay members on the governing boards of PCGs
- To explore the developing role of the lay member in relation to the functions of the PCG i.e., health improvement, service development and commissioning
- To explore different attitudes to the concept of public involvement utilising professional and lay perspectives
- To identify effective strategies for public involvement in relation to the functions of the PCG

Proposed Data Collection Tools

It is suggested that the research strategy utilises both quantitative and qualitative approaches in addressing the research question and its objectives, the following research tools are suggested: -

1. Questionnaire

2. Semi-structured interviews

3. Case Study

1. Questionnaire

A questionnaire combining open and closed questions would be utilised to provide data in relation to lay members. Data collected would include demographic details such as age, sex, ethnic origin, and social class. Also data would be collected on developing roles and responsibilities of lay members on governing boards of PCGs as well as their level of involvement in certain key areas of PCG functioning - where public involvement is seen as important i.e., commissioning of services, prescribing, health improvement programme, primary care development, information management, clinical governance and specific public involvement initiatives/public relations.

Sample Group

There are 481 lay members serving on governing boards of PCGs, it is suggested that 10% is an appropriate sample group i.e., 50. Lay members participating in the research project would be identified and approached using random sampling – use of follow up letters and a second questionnaire as well as telephone call could increase response rate.

Health authorities could also be approached to provide documentation relating to the 'person specification' utilised in recruiting lay members to the governing boards of PCG. There are 100 health authorities.

2. Semi-structured Interviews

Semi-structured interviews will be utilised with a smaller sample of lay members. This may include one to one interview as well as focus groups, the researcher must acknowledge the time restraints placed on lay members and that access to lay member meetings may be a useful source of data as well as one to one contact. Potential areas for interview schedule are highlighted below: -

- Motivation to join PCG
- Experiences as member of governing board member
- Perceptions of public involvement
- Main priorities regarding public involvement
- Strategies for public involvement

Sample Group

If possible sampling would be in different geographical areas i.e., Bradford, Liverpool, Leicester, London. Suggested sample size for individual semi-structured interviews – 20 [5 per area].

3. Case Study

It is suggested that one PCG is utilised for a longitudinal study, to study the development and implementation of public involvement initiatives over an 18-month period from September 1999 to April 2002. It is suggested that the following methodology be incorporated: -

- Observation – PCG governing board meetings and subgroups, particularly those, which are, involved with patient/public participation initiatives.

- Analysis of documentation – such as strategic proposals for public involvement, specific performance indicators related to public involvement i.e., client/carer experience, equal access, complaint procedures, client surveys
- Interviews – with board members, staff, clients regarding their perceptions/ philosophy of public involvement

The functions of the PCG may form a specific framework in utilising the above tools; **specific** initiatives may be chosen from health improvement, commissioning, service development and followed over the 18-month period. Methodology surrounding the longitudinal should remain flexible and may change over time to accommodate changing circumstances.

[redacted] PCG has been approached to form the subject of the case study. It is a PCG within inner city London, operating at Level 2 and has professed a wish to Primary Care Trust [PCT] status in the future. The PCG was chosen as it has some devolved budgeting and decision-making powers with its Level 2 status, also it already has a draft public involvement strategy and the PCG itself lies in a culturally diverse area with varying social and health needs.

Access

Names and addressing of lay members will be collected from appropriate health authority departments for the questionnaire. Within the questionnaire respondents will be asked if they wish to form part of the sample group for semi-structured interviews.

APPENDIX TEN
Lists of Occupations (National Survey)

Table

Retired Occupations

	n	%
Lecturer	6	(1.8)
Manager	33	(9.7)
Civil servant	7	(2.1)
Consultant	7	(2.1)
Financial analyst	1	(0.3)
Teacher	23	(6.8)
Secretary	5	(1.5)
Vet	1	(0.3)
Engineer	3	(0.9)
Administrator	6	(1.8)
Sales representative	2	(0.6)
Development officer	3	(0.9)
Pubic health officer	1	(0.3)
Training officer	2	(0.6)
Clinician	2	(0.6)
Director	12	(3.5)
Accountant	1	(0.3)
Designer	1	(0.3)
Education officer	1	(0.3)
Scientist	1	(0.3)
Librarian	2	(0.6)
Investigation officer	1	(0.3)
Police officer	2	(0.6)
Social worker	1	(0.3)
Chief executive	1	(0.3)
Complaints officer	1	(0.3)
Solicitor	1	(0.3)
Pilot	1	(0.3)

Business advisor	1	(0.3)
Base	129	100

*Missing211

Table

Paid Occupation

	n	%
Development/support worker	11	(3.2)
Consultant	39	(11.5)
Director - organisation/company	14	(4.1)
Chief executive	7	(2.1)
Manager	25	(7.4)
Trainer	3	(0.9)
Trade unionist	1	(0.3)
Administrator	8	(2.4)
Solicitor	1	(0.3)
Academic/researcher	19	(5.6)
Teacher	11	(3.2)
Advisor	4	(1.2)
Steward	1	(0.3)
Mediator	1	(0.3)
School inspector	2	(0.6)
Complaints officer	2	(0.6)
Welfare officer	2	(0.6)
Farmer	1	(0.3)
Councillor	4	(1.2)
Surveyor	3	(0.9)
Personal assistant	1	(0.3)

Clinician	1	(0.3)
Interpreter	1	(0.3)
Scientist	2	(0.6)
Priest	4	(1.2)
Architect	1	(0.3)
Engineer	4	(1.2)
Public health officer	1	(0.3)
Social worker	1	(0.3)
Journalist	1	(0.3)
Craft worker	1	(0.3)
Salesperson	1	(0.3)
Accountant	1	(0.3)
Mayor	1	(0.3)
Probation officer	1	(0.3)
Project manager	1	(0.3)
Finance officer	1	(0.3)
Interview officer	1	(0.3)
Base	184	100
*156Missing		

APPENDIX 11
Public Involvement Strategy (Case Study A)

[redacted] PRIMARY CARE GROUP
User and Public Involvement Strategy

INTRODUCTION

[redacted] Primary Care Group [redacted] is committed to improving the health of our local community. The [redacted] PCG Board is charged with a number of responsibilities. We need to:

- Contribute to the Health Improvement Programme [HIMP] on health and healthcare, helping to ensure that it reflects the perspective of our local community and the experience of patients.
- Promote the health of our population, working in partnership with other agencies.
- Commission health services for patients in our community.
- Monitor performance.
- Develop primary care services by joint working and sharing skills across practices.
- Better integrate primary and community health services, working more closely with social services so that people in our community receive consistently high quality and appropriate health care services.

The [redacted] PCG Board will work to achieve improved health for people in [redacted] in a way that:

- Addresses poverty and inequality.
- Encourages sharing between practices of knowledge and skills/
- Ensures that we are seen as inclusive and not coercive.
- Ensures that a realistic scale of improvement is achieved.
- Encourages local solutions.
- Supports and develops a philosophy of continuous improvement.
- Develops a culture of serving patients and the public.
- Develops a feeling of corporate achievement throughout the PCG.
- Promotes and encourages interagency working and initiatives.

We believe that the views and ideas of the people whom we serve are central to our ability to achieve our hopes and aspirations for improved health care and better health generally in [redacted].

Our commitment to involving users and the public is demonstrated through our User and Public Involvement Strategy and the central place its takes within our Primary Care Investment Plan [PCIP] - our blueprint for how we propose to achieve our goals and aspirations for the people of [redacted]

WHAT IS CONSULTATION?

Consultation should not be confused with public involvement. The dictionary definition of to consult is 'to have regard for [a person's feelings, interests etc] in making decisions or plans; consider.'

The Community Health Council's Regulations 1996, which are part of the Statutory Instruments for the NHS in England and Wales, state that: 'it shall be the duty to consult a Council on any proposals which the Health Authority may have under consideration for any substantial development of the health service in the Council's district and on any proposal to make any substantial variation in the provision of that service.'

There has never been a definition of what constitutes a 'substantial variation' in service. It is up to health authorities to decide when a proposed change would result in a 'substantial variation' and to ensure that a formal and robust consultation exercise takes place. Paragraph (5) states that the CHC should notify the Secretary of State in writing if they are not satisfied with the length or adequacy of consultation.

If further consultation is required by the Secretary of State, paragraph (6) states 'the Health Authority shall, having regard to the outcome of such further consultation, reconsider any decision it has taken in relation to the proposal in question.'

Consultation for the Health Authority is a statutory requirement and needs to follow a formal procedure.

Specific proposals for substantial service changes arising from the Health Improvement Programme would be subject to the existing consultation procedures.

The Health Authority is legally and formally required to consult on major changes in the services and has developed a consultation policy and procedure to ensure that each change is considered in the light of the various options for consultation. Although PCG's may be taking some of the decisions, the statutory requirement is likely to remain with the Health Authority.

WHAT IS PUBLIC INVOLVEMENT?

Public involvement is a generic term used to describe ways of involving members of the public in planning, decision-making and evaluating service delivery and developments. In essence, it is on-going two-way dialogue between the public and the PCG. Public involvement is more extensive than the formal consultation process about a decision of a health authority or PCG described above.

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The PCG will need to balance the many opinions of lay and professional people that there will be about most issues. In taking decisions, the PCG Board needs to explain publicly their reasons for them. Knowing what local people think is an important part of the decision-making process. Very often a whole range of views will be expressed and the PCG Board will need to show how it has taken these views into account.

WHY ARE WE COMMITTED TO USER AND PUBLIC INVOLVEMENT?

The New NHS White Paper 'Modern and Dependable' makes it clear that health and health care services need to be improved and health inequalities reduced so that patients receive similar high standards of care and health outcomes no matter where they live.

It is recognised that there are a significant number of patients and members of the public whose confidence in the NHS has diminished over recent years. It is also recognised that the general health of local communities, their ability to access appropriate health care and health outcomes generally vary widely in different parts of the country and in different sections of our community.

Greater user and public involvement is therefore an integral feature of the new NHS, if public confidence is to be rebuilt and appropriate health care delivered that properly and adequately meets patients' needs.

There is good evidence that involving users in planning services leads to more appropriate services with better uptake, particularly when marginalised groups are involved. There is also good evidence that bringing people together to work on issues improves their health.

At [redacted]PCG, our commitment to involving users and the public is underpinned by the following key principles:

- ✔ WE WANT TO BE ACCOUNTABLE TO THE PEOPLE OF [redacted] FOR THE QUALITY AND RANGE OF HEALTH CARE SERVICES THAT ARE AVAILABLE TO ALL SECTIONS OF OUR COMMUNITY.
- ✔ WE WANT TO HAVE DECISION-MAKING PROCESSES THAT ARE OPEN SO THAT THE PUBLIC MAY UNDERSTAND WHY CERTAIN DECISIONS HAVE BEEN TAKEN, EVEN THOUGH THEY MAY NOT AGREE WITH THE DECISION ITSELF.
- ✔ WE WANT TO DEVELOP A GREATER LOCAL UNDERSTANDING OF THE ISSUES INVOLVED IN MAJOR SERVICE CHANGES.
- ✔ WE WANT TO INVOLVE PEOPLE AND COMMUNITIES AS CITIZENS IN STRATEGIC DECISION-MAKING TO ENHANCE OUR ACCOUNTABILITY TO THE POPULATION WE SERVE.
- ✔ WE WANT USERS AND THE PUBLIC TO BE INVOLVED IN SETTING AND AGREEING THE PCG'S PRIORITIES FOR THE LOCAL COMMUNITY.
- ✔ WE WANT BETTER QUALITY AND MORE RESPONSIVE SERVICES THROUGH LISTENING TO AND UNDERSTANDING THE NEEDS AND WISHES OF HEALTH SERVICE USERS AND INVOLVEMENT OF THEM IN SERVICE PLANNING.

- ✔ WE WANT USERS AND THE PUBLIC TO HELP IN MONITORING THE QUALITY AND RANGE OF SERVICES WE PROVIDE AND IN EVALUATING AND REVIEWING HEALTH CARE IN OUR COMMUNITY.
- ✔ WE WANT TO INVOLVE LOCAL PEOPLE AND OTHER KEY STAKEHOLDERS IN DEVELOPING COMMUNITY-LED SOLUTIONS BECAUSE WE RECOGNISE THAT THE PROVISION OF HEALTH CARE CANNOT ALONE IMPROVE OUR COMMUNITY'S HEALTH - WORKING IN PARTNERSHIP WITH A RANGE OF DIFFERENT AGENCIES IS ALSO NEEDED.

We firmly believe that the contribution to be made by users, the public and other stakeholders in the work of [redacted]PCG will be critical to the overall achievement of our aim to improve the health of people in South Lewisham.

WHO ARE OUR PUBLIC?

SLPCG seeks to conduct its affairs in a manner that is accountable, open, fair, responsive, equitable and inclusive of all sections of our community. We want to involve the public as widely and as appropriately as possible to help us to achieve this.

We also want to make a clear distinction between 'users and the public' and 'other stakeholders'. We believe that users and the public will bring a different but equally important perspective to our work than other stakeholders. The views and opinions of users and the public may well differ from the views and opinions of our other stakeholders and it is important that we ensure that their views are given equal weight in our decision-making, service planning monitoring and evaluation processes.

In order to achieve this, therefore, we will separate users and the public quite distinctly from other stakeholders so that all our processes reflect these different perspectives and can be monitored and evaluated independently of each other.

We intend the term 'users and the public' to be as wide and inclusive as possible and will be drawing from a range of people, for example:

- Patients - past, current and potential.
- Carers - adult carers, parent carers, young carers.
- Local patient and carer groups.
- Other local support and self-help groups.
- Pressure groups.
- Patient liaison groups.
- Patients on the waiting list.
- Relatives and friends of patients and/or carers.
- People at risk.
- Advocates put forward by individuals to speak on their behalf.
- Health Panels.
- Lewisham Citizen's Panel.
- Black and Minority Ethnic groups.
- Refugees.
- Homeless people.

This list is not intended to be exhaustive and we would wish to include other sections of our community who may not be identified within these broad categories.

WHO ARE OUR STAKEHOLDERS?

In the broadest sense, our stakeholders will be those people or organisations who have a 'stake' or interest in ensuring that [redacted]PCG achieves the aims and objectives it has set and improves the health of all people in our community.

In this respect, users and the public will also be stakeholders. However, because the nature of their interest may sometimes differ from the nature of the interest of organisations with whom we would wish to work jointly to promote better health in [redacted], we believe it is important to maintain a distinction so that the voices of all our different stakeholders can be heard. Our Stakeholder Involvement Strategy will reflect this different perspective.

We will seek to ensure that our stakeholders are also drawn from a wide range or partners who share our vision of improved health for all sections of our community, for example:

- [redacted] Community Health Council.
- Individual GP practices.
- [redacted] Health Authority.
- Community health professionals.
- [redacted] Hospitals.
- [redacted] Council - Social Services, Housing, Environment, Education, Leisure.
- Occupational Health Services.
- Voluntary Organisations.
- Community Development Agencies.
- Community Care Forums.
- Community and Mental Health Trusts.
- Health Action Zone.
- Healthier [redacted]

This list is not intended to be exhaustive and we would wish to include other stakeholders who may not be identified within these broad categories.

KEY AIM OF OUR USER AND PUBLIC INVOLVEMENT STRATEGY

The overall aim of our User and Public Involvement strategy is to give health back to our community. We want people to contribute to the development and improvement of health services generally and, in particular, we want people to feel in control of their health care when they need to use our health services - whether it be a visit to the GP or as a hospital inpatient.

Just as we want to work in partnership with other stakeholders, we want health professionals to work in partnership with their patients and their carers so that excellent outcomes can be achieved in every respect - from the very first encounter with health staff to improved and consistent outcomes in treatment. We want patients to feel that their experience of health care in Lewisham has been a good one each and every time.

How Will We Achieve Our Aim?

We will need involvement from users and the public every step of the way - we cannot achieve our aim alone. We need people to become active in our work and we will need regular feedback and input into a whole range of mechanisms that we will be developing under our User & Public Involvement Strategy.

The [redacted]PCG Board intends that, in practice, our Strategy can demonstrate:

Openness	♦ The public can attend meetings of the Board and contribute to appropriate issues debated by the Board. ♦ The public can contribute to decisions and understand our decision-making processes.
Accountability	♦ The public can expect to have reasons for decisions taken by the Board to be explained to them - within the constraints of confidentiality or legal issues. ♦ Mechanisms will be developed to provide the public with ways of questioning Board decisions where their decisions do not reflect the majority of the views of the public.
Accessibility	♦ Mechanisms are in place to ensure that the public can attend, understand and contribute to Board debates. ♦ Systems are in place to ensure that the views of the public are effectively fed back to the PCG Board.
Clinical Governance Involvement	♦ The public's views are sought about the quality of health care services and the quality issues that they would wish to prioritise for improvement. ♦ The public are engaged in setting, monitoring and evaluating standards of care in the health service. ♦ The public are engaged in determining and prioritising service developments within their local health service.
Inclusiveness	♦ Users and the public are involved in formal consultation processes. ♦ A range of different, appropriate and effective mechanisms are developed for involving the public. ♦ The 'hidden voices' of minority community groups are heard to ensure that inequalities and disadvantage are appropriately addressed.

JOINT WORKING	♦ Existing expertise of working with the public are built on and developed to best effect. ♦ Our Public Involvement Strategy is linked to the public involvement work on the Health Improvement Programme, the Health Action Zone and Joint Investment Plans etc.
SHARED LEARNING	♦ Awareness of good practice - both locally and nationally - is developed and used to inform our own practice. ♦ Good practice identified locally is shared with other PCGs within [redacted] wherever possible.
CORPORATE RESPONSIBILITY	♦ Public involvement has a named lead Board member and will be the corporate responsibility of the PCG Board. ♦ Board reports and decisions will explicitly identify any public involvement perspective or implications where appropriate.
EFFECTIVENESS	♦ The PCG will develop a Public & User Involvement Annual Plan linked to its Primary Care Investment Plan. ♦ Progress in our User & Public Involvement work will be evaluated annually and the results published in the Annual Report. ♦ Users and the public will be given feedback on the effect of their involvement.

PUBLIC INVOLVEMENT MECHANISMS

A wide range of mechanisms have been used nationally to involve the public. [redacted]PCG intends to build on good practice and, where possible, develop new and effective ways of involving the public which may be more appropriate to our local community or particular groups of people within South Lewisham.

The type of mechanism used will depend on a variety of factors - such as the nature of the involvement; the type of people we want to involve; the specific issues that we want to address; the solutions we are seeking to find; financial considerations.

Set out as an Appendix to this Strategy are a range of User and Public Involvement mechanisms which may be used by [redacted]PCG to ensure that users and the public and properly and fully involved.

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USER AND PUBLIC INVOLVEMENT FEEDBACK

[redacted]PCG believes that it will be critical to ensure that users and the public are given feedback about the results of their involvement.

We believe this is important, not only as a way of demonstrating accountability to the public, but because it is courteous to those who have given up their valuable time to participate and contribute their views.

Furthermore, we firmly believe that if users and the public are to be encouraged to become involved, we need to have robust feedback mechanisms in place to demonstrate that their involvement has been worthwhile and borne out of our genuine desire to seek their views and build them into the overall development of health care services in [redacted]

It is our intention that feedback will help to promote confidence and trust. [redacted]PCG believes that trust and confidence will be the key building blocks from which we can develop sustainable and fruitful relationships with the people in our community.

MONITORING, EVALUATION AND REVIEW

[redacted]PCG recognises that monitoring, evaluating and reviewing the effectiveness of our User and Public Involvement Strategy will be critical to:

- gaining a greater understanding of local needs, issues and concerns.
- becoming more open, accessible and accountable to the people whom we serve.
- the development of better quality and more responsive health services.
- improved health outcomes for people in our community.

To this end, [redacted]PCG will:

- identify the objectives we aim to achieve in our User & Public Involvement Annual Plan.
- evaluate each user and public involvement activity against specified outcomes.
- use the results of such evaluation to inform the development of our User & Public Involvement Strategy and Annual Plan.
- undertake a formal review and evaluation of our User & Public Involvement Annual Plan.
- publish the results of this review in our Annual Report.

APPENDIX 12
Matrix of Care

MATRIX OF CARE APPROACH

CHD – Year 1	PRIMARY CARE	SECONDARY CARE	SOCIAL CARE	COMMUNITY CARE	SOCIAL EXCLUSION & INEQUALITIES	PUBLIC INVOLVEMENT	PARTNERSHIP DEVEL.
• Investigate options for establishing a direct access ECG and stress testing service at [redacted] and 24hr tapes with appropriate guidelines. If possible, establish new service by Summer 2000.	✓	✓					
• Over the next twelve months develop guidelines for referral for Cardiac Echo and review requirements for a Direct Access service;	✓			✓			
• Primary Health Care Teams (PHCTs) to review resources and training needs re CHD and disease specific audit and needs assessment;	✓						
• PHCTs to develop practice based disease registers by April 2001;	✓						✓
• Collection of standardised data across the PCG, such as morbidity mortality data, simple audit data for monitoring standards;	✓	✓		✓			
• Partnership working to be encouraged to develop care, resources and service provision such as prescriptions for exercise, Healthy walks, healthy workplaces etc with local agencies, voluntary groups, statutory bodies etc; partnership working to be encouraged to develop primary and secondary prevention work;	✓	✓		✓		✓	
• Local work between PHCTs, local Prescribing Advisor and Community Pharmacists or local CHD prescribing protocols and guidelines;	✓						
• Primary care team to develop practice based computer system, preferably those that can accommodate the NHS Net and can link more easily with other crucial systems;	✓						
• PCG to ensure training available for on the appropriate clinical screens and how they will link;	✓	✓					
• Link in with [redacted] work on the use of standardised Read codes, with an understanding on the structures required to update and maintain them.	✓	✓		✓			
• Develop a smoking cessation programme across [redacted] PCG;	✓	✓		✓			✓
• Develop education programme re: antenatal nutrition;							
• Ensure all CHD work linked in to Diabetes work programme.	✓	✓		✓			
• Undertake a review of access to cardiac rehab;	✓	✓					
• Encourage Practice to complete the Aspirin Audit;							
• Link Cardiac Audit and Disease Register development to PHCG contract for quality in Year 2;	✓	✓					
• Develop local guidelines for ACE Inhibitors and Beta Blockers;	✓	✓					
• Link Cardiac and Clinical Governance agenda re: role of Cardiac Support Nurse;	✓	✓		✓			
• Assess the added value/benefits of introducing nurse lead cardiac clinics;	✓	✓					
• Review rates of interventional cardiology locally and alight to NSF;							
• Develop and focus on user involvement, develop user focus groups, information sharing and patient held record card and guidelines;							

MATRIX OF CARE APPROACH

CHD – Year 2 & 3	PRIMARY CARE	SECONDARY CARE	SOCIAL CARE	COMMUNITY CARE	SOCIAL INCLUSION & EQUALITIES	PUBLIC INVOLVEMENT	PARTNERSHIP DEVEL.
• Collection of standardised data across the PCG, such as morbidity mortality data, simple audit data for monitoring standards;	✓		[redacted]				✓
• Undertake a review of access to cardiac rehab;	✓	✓		✓		✓	
• Develop local guidelines for ACE Inhibitors and Beta Blockers;	✓	✓					
• Assess the added value/benefits of introducing nurse lead cardiac clinics	✓	✓		✓			
• Develop a focused approach to developing services for the Asian population, which has a high prevalence of CHD. Develop health education days in community and social centres using dieticians, hospital specialists and GPs.							
• Explore the development of a project to develop shared criteria for prioritising patients on waiting lists.							

MATRIX OF CARE APPROACH

ELDERLY CARE – Year 1	PRIMARY CARE	SECONDARY CARE	SOCIAL CARE	COMMUNITY CARE	SOCIAL INCLUSION &/or INEQUALITIES	PUBLIC INVOLVEMENT	PARTNERSHIP DEVEL.
• Encourage participation in local elderly working group;		✓	✓	✓			
• Ensure elderly care a key issue for discussion across Neighbourhoods;	✓						
• Feedback initial work on the local action plan by the [redacted] Elderly working group to Neighbourhoods;	✓						
• Work towards more integrate teams with primary care, looking at resources at Neighbourhood level;			✓				
• Review practice staffing spending (1999/2000) with a view to introducing a link nurse between primary, secondary and social/community care for elderly services;	✓	✓	✓	✓			✓
• Encourage closer working between PHCTS and District Nurses, Older Adults Social Services Team and the EMI teams;	✓		✓	✓			
• [redacted]PCG will work closely with the [redacted] Social care and Health teams and the [redacted] EMI team to align them more closely to the Neighbourhood Groups;	✓						
• Agree key audits, see links to other disease groups osteoporosis in particular and the need to reduce the risks of fractures in the elderly. Good evidence now exists that one tablet of calcium and vitamin D is effective in reducing the risks of fracture (Repeat prescribing);	✓			✓			
• Wide publicity for winter flu vaccine campaign for high risk groups. Target all over 65s for flu vaccine. Ensuring District Nurses are fully involved in the process.	✓	✓	✓	✓		✓	✓
• Commence work on reductions in average length of stay, work with [redacted] and [redacted] on the impact at planned reductions in average length of stay;	✓	✓		✓	✓		
• Finish evaluation of winter pressures schemes and share findings across all agencies;							
• Lead role in debate on pilot project with [redacted] for exploring the benefits of pooled budgets;			✓				
• Introduce electronic discharge notes and pilot across elderly care with primary care and [redacted]			✓				
• [redacted]PCG participate in debate on District Nurse liaison between [redacted] and [redacted] to help improve care							
• Work with [redacted] and [redacted] on the impact at planned reductions in average length of stay;							
• Closer working between primary and social care on developing the understanding of the nurse home contract; Work closley with the Health Authority and Community Trust							

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MATRIX OF CARE APPROACH

ELDERLY CARE – Year 1	PRIMARY CARE	SECONDARY CARE	SOCIAL CARE	COMMUNITY CARE	SOCIAL INCLUSION & INEQUALITIES	PUBLIC INVOLVEMENT	PARTNERSHIP DEVEL
• Ensure multi-disciplinary and multi-agency focus for all local work on elderly care. [redacted] PCG to act as the linchpin and bring agencies together;							✓
• Obtain feedback from [redacted] "Open Space" conference on issues for the elderly in [redacted]. Understand how a range of cultures in Lewisham could steer/shape elderly services;					✓	✓	
• Work with local voluntary groups to develop projects to reduce isolation and access issues particularly for lone elders of a multi-cultural background;					✓	✓	
• Focus work on lone elders to particular housing estates [redacted]					✓		
• [redacted] PCG to establish a community partnership sub group and invite the chair of the local pensioners forum to be a member;						✓	
• Both of the above to look at the elderly care agenda and make discussions of how best to work with the public and voluntary section on this issue.						✓	
• Ensure multi-disciplinary and multi-agency focus for all local work on elderly care. Utilise the needs assessment on the housebound elderly conducted by [redacted] PCG to act as the linchpin and bring agencies together;						✓	✓
• Much joint partnership work has been done in this area. It is important not to step on the toes of other agencies or to reinvent the wheel; it is also important that we should not allow people agencies to be territorial.							✓
• Use links with Regeneration teams and social care and health as prime focus;							✓
• Ensure New Deal for communities SRB bids, PFI bids and other regeneration plans reflect the needs of this client group.							
• With [redacted] a mapping of all local groups discussing elderly services and review accountability and roles.							
• Implement the findings of the National Bed Inquiry	✓	✓	✓	✓		✓	✓

MATRIX OF CARE APPROACH

ELDERLY CARE – Year 2	PRIMARY CARE	SECONDARY CARE	SOCIAL CARE	COMMUNITY CARE	SOCIAL INCLUSION & INEQUALITIES	PUBLIC INVOLVEMENT	PARTNERSHIP DEVEL
• Evaluate the role of the Elderly link worker and advise re: continuity;	✓						
• Develop a baseline and a clear understanding of the resource picture for each Neighbourhood and link to commissioning round with both [redacted] and practice staffing process. Agree Neighbourhood resourcing principles across the Neighbourhoods and focus on HIMP/Client group targets;	✓						
• Ensure practices are moving towards being able to support the Booked Admissions programme with [redacted]	✓						
• Dissemination of audit findings. Agreement of key audits for the year;	✓						
• Wide publicity for flu vaccine for high risk groups, bring practices together to provide better flu coverage;	✓						
• Introduction of plan for long term reduction in average length of stay;		✓					
• Pilot of the Booked Admissions programme. [redacted] to support primary care in terms of the resources primary care will require to deliver this role;		✓					
• Continuation of joint work across local health sectors on developing supported discharge and communication;		✓					
• Lead role in pooled budget pilot.		✓					
• Work towards aligning of social care teams boundaries to Neighbourhoods;		✓					
• Development at operational level of joint work between SSD commissioning teams and local practices on nursing home issues.			✓				
• Alignment of community nursing teams to Neighbourhoods with joint view with [redacted] PCG on Neighbourhood resourcing and future planning;			✓				
• Development of supported discharge and communication group to reflect long term planning goals.	✓			✓			
• Practices to review levels of access to care particularly for this client group;	✓						
• Implement key issues from scoping work in Year 1.				✓			✓
• Practices to include one element of public involvement in their business plan. [redacted] PCG to ensure a number of these focus on elderly care;	✓	✓	✓	✓	✓ ✓	✓	✓ ✓
• Implement findings of the [redacted] Elderly Review and the [redacted] needs assessment in relation to Community Development schemes.						✓ ✓	✓
• Implement findings from initial work in Year 1;	✓						
• Ensure [redacted] PCG a joint lead on key regeneration issues;			✓	✓	✓	✓	
• Develop a fruit and vegetable co-operative in [redacted] particularly for Elders and young families;						✓	

MATRIX OF CARE APPROACH

ELDERLY CARE – Year 2	PRIMARY CARE	SECONDARY CARE	SOCIAL CARE	COMMUNITY CARE	SOCIAL INCLUSION & EQUALITIES	PUBLIC INVOLVEMENT	PARTNERSHIP DEVEL
• Work towards more integrate teams with primary care, looking at resources at Neighbourhood level;			✓				
• Lead role in debate on pilot project with SSD for exploring the benefits of pool budgets;	✓	✓		✓			

MATRIX OF CARE APPROACH

ELDERLY – Year 3	PRIMARY CARE	SECONDARY CARE	SOCIAL CARE	COMMUNITY CARE	SOCIAL INCLUSION & EQUALITIES	PUBLIC INVOLVEMENT	PARTNERSHIP DEVEL.
• Implementation of average length of stay reductions at [redacted]		✓					
• Continued development of Neighbourhood integration of Neighbourhood teams;	✓	✓	✓	✓			
• Establish commissioning priorities for Elderly care on a Neighbourhood basis;	✓	✓	✓	✓		✓	
• Implement key findings for Year 2;	✓	✓	✓	✓			
• Agree key audits for the year and review action arising from those in Year 2.	✓	✓	✓	✓			

MATRIX OF CARE APPROACH

SEXUAL HEALTH – Year 1, 2 & 3	PRIMARY CARE	SECONDARY CARE	SOCIAL CARE	COMMUNITY CARE	SOCIAL INCLUSION & EQUALITIES	PUBLIC INVOLVEMENT	PARTNERSHIP DEVEL
• **Commissioning** (a) Develop an LTSA: Link to [redacted] agreed minimum standards for contraceptive services; (b) Take an active part in a [redacted] commissioning/advisory structure (c) Improve links between Family Planning services and GUM services Link to [redacted] agreed minimum standards for contraceptive services; (d) Work in partnership with others to take forward the 'Teenage Pregnancy & Parenthood in [redacted] Report March 2000.	✓			✓		✓	
• **'Develop a Confidentiality' policy** Use RCGP toolkit; Link to DH guidance and receptionist/staff training; Link to [redacted] agreed minimum standards for contraceptive services;	✓	✓		✓		✓	
• **Practice specific review of contraceptive prescribing and IOS claims** Data already collected by HA ; Potential positive financial impact Link to Faculty guidance on OCP prescribing/coil insertion; Link to [redacted] agreed minimum standards for contraceptive services could be included in [redacted]	✓	✓	✓	✓	✓	✓	✓
• **PCG - Staff training Needs Assessment** Link to [redacted] agreed minimum standards for contraceptive services; Link to visible confidentiality policy; Consider link to PMS review; Could be included in [redacted]	✓	✓	✓	✓			✓
• **Link with PMS practices that have sexual health service developments** This is an opportunity to improve provision in primary care, improve access, as well as developing partnership working	✓	✓		✓			
• **Information and data handling** To include working with community and secondary providers to collect ethnicity data; to improve and link information systems	✓		✓		✓		✓

MATRIX OF CARE APPROACH

SEXUAL HEALTH – Year 1, 2 & 3	PRIMARY CARE	SECONDARY CARE	SOCIAL CARE	COMMUNITY CARE	SOCIAL INCLUSION & EQUALITIES	PUBLIC INVOLVEMENT	PARTNERSHIP DEVEL
• **STI in General Practice Project** This was due to pilot in [redacted] – need to ensure that it is appropriate to primary care needs rather than being driven by the specialist services. To include: sexual history taking, contact tracing from primary care, technical details of specimen collection. Could be included in [redacted] Could be included in expanded [redacted] quality standards work.	✓		✓		✓		✓
• **Quality Protects/Sure Start** Work with quality protects and sure start to maximise opportunities with new initiatives to improve sexual health.	✓			✓			
• **Education: and National Healthy School Standards** (a) Work with local schools to take this up (many already have, as [redacted] is a national pilot area); Develop effective partnerships working more with schools, school nurses and education. (b) Use these standards as the basis for any more detailed work in schools. (c) Strengthen links with the Healthy Schools partnership	✓		✓		✓		✓
• To support current HAZ initiatives and to identify any opportunities for further collaborative work;	✓			✓			
• **Emergency Contraception** Link to prescribing review (a) Mystery shopper survey – which could be expanded out; Learn from others with regard to good practice, work to role out Manchester Project. (b) Progestogen EC: Note current licensing applications; (c) Pre-prescribing by GPs. Note potential cost implications. (d) Wider availability of EC e.g. pharmacies, school nurses. There are licensing applications being considered which may well change the situation. Link to [redacted] agreed minimum standards for contraceptive services.	✓				✓	✓	✓

MATRIX OF CARE APPROACH

CHILDREN & YOUNG PEOPLE - Year 1, 2 & 3	PRIMARY CARE	SECONDARY CARE	SOCIAL CARE	COMMUNITY CARE	SOCIAL INCLUSION & EQUALITIES	PUBLIC INVOLVEMENT	PARTNERSHIP DEVEL
Immunizations							
• To work in partnership with [redacted] health visiting and school nursing services in achieving the new Meningitis C immunization targets;				✓			
• To identify areas of poor uptake of primary immunizations MMR, and pre-school boosters at practice and neighbourhood level, to proactively work with [redacted] and the PCG. Clinical Governance Manager to achieve improvement of information and standardisation of data;	✓			✓			
• To identify practices with good uptake of immunizations to be able to share areas of good practice with under-achieving practices and support this implementation;	✓						
• To link with [redacted] public health department and [redacted] thoracic team to undertake a clinical risk assessment on tuberculosis and the risk to children and families given the reduced availability of neonatal BCG and school health programme.	✓			✓			
Working to optimise the Health of Children –Child Health Promotion							
• To work in partnership with [redacted] health visiting and school nursing services to ensure that targets for child health promotion/surveillance are achieved. To work with [redacted] to complete the [redacted] contracted audit on child health promotion;	✓			✓			
• To work in partnership with [redacted] Child Health Directorate to ensure that children with special needs are identified, are referred and receive appropriate secondary and tertiary services within acceptable time frames;	✓			✓			
• That [redacted] PCG actively support the relocation of Priory Manor and the establishment of a comprehensive community children's health record second tier service to incorporate mental health services for children (currently at [redacted] Park);	✓			✓			
• To work with [redacted] in commissioning appropriate responsive timely child mental health services;	✓			✓	✓		
• Working with practices and community nurses at primary tier;	✓	✓					
• Providing responsive local secondary services with a reduction in waiting times for children and families with the aim of reducing exclusion, isolation, associated morbidity and youth offending.	✓			✓	✓	✓	✓
Children in Need							
• To jointly work with social services in the development of services for children within the remit of Quality Protects to ensure that the needs of children "looked	✓		✓	✓	✓	✓	

MATRIX OF CARE APPROACH

CHILDREN & YOUNG PEOPLE – Year 1,2 & 3	PRIMARY CARE	SECONDARY CARE	SOCIAL CARE	COMMUNITY CARE	SOCIAL INCLUSION & EQUALITIES	PUBLIC INVOLVEMENT	PARTNERSHIP DEVEL
After "/in care are properly addressed with the Possibility of fast-tracking to access specific health Services as required e.g. psychological services or Statementing needs;							
• To develop and support a training programme for all practice staff on child protection and good practice, working with Social Services and [redacted]	✓		✓	✓	✓		
• To ensure that all children currently fostered/in care/looked after within [redacted]PCG are registered with a GP.	✓		✓	✓			
Partnership and Children							
• To take an active role in the Partnership Children Services Group to promote a multi-disciplinary approach in the delivery of services;	✓					✓	✓
• To take an active role in the development of the Sure Start project in [redacted]	✓		✓	✓	✓	✓	✓
• To support current HAZ initiatives and to identify any opportunities for further collaborative work;	✓		✓	✓			
• To work with [redacted] to develop the role of the youth project worker within practices;	✓		✓	✓			
• To work in partnership with the Asylum Seekers team and the Refugee Outreach Team to identify families with children currently seeking asylum/refugee status and support work with [redacted], Education and practices within [redacted]PCG to ensure needs are met/access to primary care and education are achieved. Also to identify where there are "hot-spots" of unmet needs or pressures on current services;	✓		✓	✓			
• To work with [redacted] and [redacted] to identify levels of teenage pregnancies within neighbourhoods, map current resources to address this and develop services which are responsive to their needs e.g. parenting programmes targets at teenagers both antenatal and post-natal;	✓						
• [redacted]PCG to participate in the debate and review of services in respect of the therapeutic creches and hospital liaison services;	✓		✓	✓	✓	✓	✓
• To encourage closer working between neighbourhoods, PHCTs, health visiting and school nursing to identify resources, work towards better team integration within community nursing, using individual skills most effectively;	✓		✓	✓			
• To understand resources related to the delivery of children's services by neighbourhood where possible and link to the commissioning round with both [redacted] and practice staffing process (N.B. *some services are [redacted] wide such as paediatric homecare and community thoracic team);	✓		✓	✓			
• To establish firm links with hospital/community maternity services on the delivery of : - ante-natal care; - post natal care;	✓	✓	✓	✓	✓	✓	✓

MATRIX OF CARE APPROACH

CHILDREN & YOUNG PEOPLE – Year 1,2 & 3	PRIMARY CARE	SECONDARY CARE	SOCIAL CARE	COMMUNITY CARE	SOCIAL INCLUSION & EQUALITIES	PUBLIC INVOLVEMENT	PARTNERSHIP DEVEL.
- promotion of HIV testing and information for parents;	✓	✓	✓	✓	✓	✓	✓
- promotion of [redacted] screening;	✓	✓	✓	✓	✓	✓	✓
- alignment of midwives to practices and to be involved in the commissioning process.	✓	✓		✓			
• Support to children and families. Work with families in schools, playgroups, creches to develop parenting skills help prevent mental illness. Map resources for child mental health services.	✓	✓	✓	✓	✓	✓	✓
• Improve and build upon health education/promotion, particularly healthy eating and ensuring good nutritional advice is offered and publicised. Work with schools to develop healthy eating policies. Build on the work in [redacted] and the work of PMS practices	✓	✓	✓	✓	✓	✓	✓
• To work with the public and voluntary sector to develop a more inclusive approach to the delivery of children's services;	✓	✓	✓	✓	✓	✓	✓
• To work with [redacted] and Early Years on receiving any feedback on current services, including good and poor practice.	✓	✓	✓	✓	✓	✓	✓
• Dcvelop the role of users, panel of young people to advise and assist in the development of services.	✓	✓			✓	✓	✓
• Develop links with [redacted] Domestic Violence Forum, to ensure services are sensitive to and meet the needs of families experiencing domestic violence	✓	✓	✓		✓	✓	✓
• Work with partners to develop support to children who carers and children of parents with mental illness.	✓	✓			✓	✓	✓
Accidents							
• To develop a joint local strategy by April 2001.							
Drug, Alcohol and Smoking							
• To develop a local joint strategy by April 2001.							

MATRIX OF CARE APPROACH

MENTAL HEALTH – Year 1	PRIMARY CARE	SECONDARY CARE	SOCIAL CARE	COMMUNITY CARE	SOCIAL INCLUSION & EQUALITIES	PUBLIC INVOLVEMENT	PARTNERSHIP DEVEL.
[redacted] PCG recognises the role of the new National Service Framework for this client group. In addition it is a joint partner on the mental health integrated commissioning board for [redacted] This group has prepared a detailed strategy implementation plan that includes substantial comment from Primary Care representatives. This implementation Plan has South [redacted] PCG's whole-hearted support. The attached Matrix does not attempt to replace this document. The Matrix merely attempts to outline the key issues as noted in the main document and to highlight the particular areas in which [redacted] may have ability to influence or encourage delivery.							
• Joint work to review access to mental health services in primary care (NSF standard 2);	✓		✓	✓	✓	✓	✓
• Prepare action plan for increasing access to primary care and on-referral to specialist opinion (NSF standard 2);	✓		✓	✓	✓	✓	✓
• Publicise the role of NHS Direct (NSF standard 3);	✓		✓	✓	✓	✓	✓
• PCG to monitor waiting times for specialist referral;	✓		✓	✓	✓	✓	✓
• PHCTs to support patients locally and put them in touch with local voluntary/self help groups;	✓						
• Practice Prescribing Actions Plans to focus on prescribing of antidepressants, anti psychotics and benzodiazepines confirming to clinical guidelines;	✓						
• Develop a strategy for the development of the role of user groups in partnership working, planning and developing services. Develop an understanding of the user perspective and providing greater input across all service areas;	✓	✓	✓	✓		✓	✓
• Develop and introduce a fair access strategy for disadvantaged and minority groups.	✓	✓	✓	✓	✓	✓	✓
• Introduce training for practice staff on culturally appropriate mental health issues;	✓	✓			✓	✓	✓
• Improve communication between PHCTs and [redacted] through:-	✓			✓	✓	✓	✓
Better quality and swifter discharge information	✓			✓	✓	✓	✓
Development of shared protocols jointly developed Between primary care and [redacted] easier access to Consultants re sectioning.							
• Develop shared criteria for referral, assessment of urgency and risk of self harm between primary care and [redacted]	✓	✓			✓	✓	✓
• Develop standardised list of Read codes to help with audit;	✓	✓			✓	✓	✓
• Extend Welfare Rights services to all practices in [redacted] by April 2001;	✓	✓			✓	✓	✓

MATRIX OF CARE APPROACH

MENTAL HEALTH – Year 1	PRIMARY CARE	SECONDARY CARE	SOCIAL CARE	COMMUNITY CARE	SOCIAL INCLUSION & EQUALITIES	PUBLIC INVOLVEMENT	PARTNERSHIP DEVEL
• On a joint partnership basis explore the possibilities of establishing a meeting place for users in each Neighbourhood;	✓	✓	✓	✓	✓	✓	✓
• Work in partnership to develop effective strategies to reduce available and inappropriate addmissions and reduce suicides for people in contact with health services;	✓	✓	✓		✓	✓	✓
• Work with [redacted] to develop a common information base that access to a care programme approach.	✓	✓				✓	✓

MATRIX OF CARE APPROACH

MENTAL HEALTH – Year 2 & 3	PRIMARY CARE	SECONDARY CARE	SOCIAL CARE	COMMUNITY CARE	SOCIAL INCLUSION & EQUALITIES	PUBLIC INVOLVEMENT	PARTNERSHIP DEVEL
• Review options for developing a 24 hour service for those with a current mental health problem (NSF standard 3);	✓		✓	✓	✓	✓	✓
• All practices to undertake Depression Audit by April 2002. Those who have completed it should undertake the post natal depression audit (or eating disorders, anxiety disorders);	✓						
• Over long term develop role of assertive outreach;				✓	✓	✓	✓
• Take a joint partnership approach to developing out of hours services;	✓						

APPENDIX 13
CPG – Work Plan

[redacted] Primary Care Group
Public Involvement and the 3-year Plan

AREA	ACTIVITY	HOW	PRIORITY
YEAR 1 Coronary Heart Disease	Partnership working to be encouraged to develop care, resources and service provision such as prescriptions for exercise, healthy walks, healthy workplaces etc with local agencies, voluntary groups, statutory bodies etc.		Note: not identified as Public Involvement in Plan.
YEAR 1 Coronary Heart Disease	Develop a local smoking cessation programme across [redacted] PCG.		Note: not identified as Public Involvement in Plan.
YEARS 2 & 3 Coronary Heart Disease	Undertake a review of access to cardiac rehabilitation.	Patient's experiences of access and service received etc?	Note: not identified as Public Involvement in Plan.
YEAR 1 Elderly Care	Commence work on reductions in average length of stay, work with [redacted] and [redacted] on the impact of planned reductions in average length of stay.		
YEAR 1 Elderly Care	Obtain feedback from [redacted] "Open Space" conference on issues for the elderly in Lewisham. Understand how a range of cultures in Lewisham could steer/shape elderly services.		
YEAR 1 Elderly Care	Work with local voluntary groups to develop projects to reduce isolation and access issues particularly for lone elders of a multi-cultural background.		Note: not identified as Public Involvement in Plan
YEAR 1 Elderly Care	Focus work on lone elders to particular housing estates - [redacted]		
YEAR 1 Elderly Care	Both of the above to look at the elderly care agenda and make discussions about how best to work with the public and voluntary sector on this issue.		
YEAR 1 Elderly Care	[redacted] PCG to establish a Community Participation Sub Group and invite the chair of the local pensioner's forum to be a member.	Done!	
YEAR 1 Elderly Care	Ensure multi-disciplinary and multi-agency focus for all local work on elderly care. Utilise the needs assessment on the housebound elderly conducted by [redacted] to act as the linchpin and bring agencies together.		Note: not identified as Public Involvement in Plan

[redacted]

YEAR 2 Elderly Care	Practices to include one element of public involvement in their business plan. [redacted]PCG to ensure that a number of these focus on elderly care.		Note: not identified as Public Involvement in Plan
YEAR 2 Elderly Care	Implement the findings of the [redacted] Elderly Review and the [redacted] needs assessment in relation to community development schemes.		
YEAR 2 Elderly Care	Develop a fruit and vegetable co-operative in [redacted] particularly for elders and young families.		
YEAR 3 Elderly Care	Establish commissioning priorities for elderly care on a Neighbourhood basis.		Note: not identified as Public Involvement in Plan
YEARS 1, 2 & 3 Sexual Health	'Visible Confidentiality' Policy	What does this mean?	
YEAR 1, 2 & 3 Sexual Health	Staff training review	What is this?	
YEAR 1, 2 & 3 Sexual Health	Links with PMS practices with an interest in sexual health. To follow on from January 25th meeting - ? who is coming from the PCG? This is an opportunity to rationalise specialist provision in primary care, as well as perhaps around partnership working.	What does this mean?	
YEARS 1, 2 & 3 Children and Young People	**Working to optimise the health of children - Child Health Promotion:** Providing responsive local secondary services with a reduction in waiting times for children and families with the aim of reducing exclusion, isolation, associated morbidity and youth offending.		
YEAR 1, 2 & 3 Children and Young People	**Children in Need:** To jointly work with Social Services in the development of services for children within the remit of Quality Protects to ensure that the needs of children "looked after"/in care are properly addressed with the possibility of fast-tracking to access specific health services as required e.g. psychological services or statementing needs.		
YEARS 1, 2 & 3 Children and Young People	**Partnership and Children:** To take an active role in the Partnership Children Services Group to promote a multi-disciplinary approach in the delivery of services.		
YEARS 1, 2 & 3 Children and Young People	**Partnership and Children:** To take an active role in the development of the Sure Start project in [redacted]		

[redacted]

YEARS 1, 2 & 3 Children and Young People	**Partnership and Children**: [redacted]PCG to participate in the debate and review of services in respect of the therapeutic crèches and hospital liaison services.		
YEAR 1, 2 & 3 Children and Young People	**Partnership and Children**: To establish firm links with hospital/community maternity services on the delivery of: ▸ ante-natal care; ▸ post natal care; ▸ promotion of HIV testing and information for parents; ▸ promotion of universal sickle cell screening.		
YEARS 1, 2 & 3 Children and Young People	**Partnership and Children**: To work with the public and voluntary sector to develop a more inclusive approach to the delivery of children's services.		
YEARS 1, 2 & 3 Children and Young People	**Partnership and Children**: To work with [redacted] and Early Years on receiving any feedback on current services, including good and poor practice.		
YEARS 1, 2 & 3 Children and Young People	**Accidents**: To develop a local joint strategy by April 2001.		
YEAR 1, 2 & 3 Children and Young People	**Drug, Alcohol and Smoking**: To develop a local joint strategy by April 2001.		
YEAR 1 Mental Health	Joint work to review access to mental health services in primary care (NSF Standard 2).		
YEAR 1 Mental Health	Prepare action plan for increasing access to primary care and on-referral to specialist opinion (NSF Standard 2).		
YEAR 1 Mental Health	Publicise the role of NHS Director (NSF Standard 3).		
YEAR 1 Mental Health	PCG to monitor waiting times for specialist referral		
YEAR 1 Mental Health	PHCTs to support patients locally and put them in touch with local voluntary/self help groups.		Note: not identified as Public Involvement in Plan
YEAR 1 Mental Health	Ensure the experience of service users and carers (including those from black and ethnic minority communities) are built into service development and commissioning.		Note: not identified as Public Involvement in Plan
YEAR 1 Mental Health	Introduce training for practice staff on culturally appropriate mental health issues.		Note: not identified as Public Involvement in Plan

YEAR 1 Mental Health	Develop standardised list of Read codes.	What does this mean?	
YEAR 1 Mental Health	Extend Welfare Rights services to all practices in [redacted] by April 2001.		
YEAR 1 Mental Health	On a joint partnership basis, explore the possibilities of establishing a meeting place for users in each Neighbourhood.		
YEARS 2 & 3 Mental Health	Review options for developing 24 hour service for those with a current mental health problem (NSF Standard 3).		
YEARS 2 & 3 Mental Health	Over long term develop role of assertive outreach.		Note: not identified as Public Involvement in Plan
YEAR 2 & 3 Mental Health	Take a joint partnership approach to developing out of hours services.		
Year 1 Primary Care Clinical Governance - Vaccination and Immunisation	Work with user groups and other organisations and school nurses to develop education/information packs for parents/carers.		
Year 1 Primary Care Cytology	To improve the uptake of cervical cytology and increase the number of practices achieving higher targets.		
Year 2 Primary Care Clinical Governance - Vaccination and Immunisation	To develop a policy to respond to the needs of parents/carers who do not take their children to be vaccinated.		
Year 2 Primary Care CHD	Systems to provide patients with results of investigations and how these results are understood.		

OTHER AREAS FOR USER AND PUBLIC INVOLVEMENT?

- Patients as teachers.
- Influencing commissioning of secondary services and standards expected.
- Monitoring and evaluation.

APPENDIX 14
Agenda Item (Case Study A)

[redacted] Primary Care Group NHS

[redacted] Primary Care Group NHS

AGENDA

[redacted] – OLDER PEOPLE

Follow-up Working Group – Wednesday 12 June 2002
from 10.30 am to 12.00 noon
at [redacted] Primary Care Group, 4th Floor - Board Room,
[redacted]

1. Welcome and introductions
2. Wards at University Hospital [redacted] –update from [redacted]
3. Prescribing issues – updates from [redacted]
4. 75+ checks – Update from [redacted]
5. Information from [redacted] attached to minutes
6. Mobile eye testing – update from [redacted]
7. Keep Well booklet - £4,000 grant from PCGs for re-printing – Report from [redacted]
8. Diabetes - Update from [redacted]
9. Date of next meeting – to be agreed

APPENDIX 15
GP Letter (Case Study A)

[redacted]

[redacted]

17 JUL 2001

11/7/01

[redacted]
Primary Care Group
[redacted]

Dear [redacted]

Re: **CONFERENCE REPORT** [redacted]

Thank you for sending me this report. A few comments:

I am not sure that the recommendations actually pull out the key issues of the more detailed conversation. Maybe you could re-visit those.

The more detailed comments and articles at the back are very salutary - I am not quite sure how we can use them but we certainly shouldn't let them disappear.

My simplest recommendation is that we ensure that the primary care aspects come to the [redacted] Mental Health Group and that the hospital aspects and the wider aspects come to the ICG. Nonetheless, I suspect that this will not be sufficient because these recommendations are not part of the NSF and therefore it would be difficult to keep them at the top of the agenda.

Any other suggestions for implementing these would be gratefully received.

All the best and thank you for this work.

Yours sincerely,

[redacted]

APPENDIX 16
Evaluation of Health Initiative Event (Case Study A)

Workshops - people were able to select a workshop of their choice. Workshop leaders came from voluntary sector agencies and health and social care professionals. Workshop topics were:

Mental health and primary care
Mental health and elderly people
Mental health and race
Mental health and young people
Hospital services for people with mental illness
Moving on – support

What was achieved? Have results been fed into decision making? How did participants benefit from being involved?

The evaluation revealed that participants felt that expectations had been met. They felt the presenters were properly informed. Feedback from participants was extremely positive. For the first time ever people with mental illness and members of the public, were able to discuss the good aspects of local healthcare and the areas which needed improvement with professionals from the public sector agencies and voluntary organisations. Again, for the first time members of the Vietnamese, Caribbean and Turkish communities participated alongside young people and elderly people. A small group of people with mental illness who were hospitalised asked to attend and were able to contribute.

A conference report written in user-friendly language, with realistic recommendations, has been produced by the planning group. The full report has been presented to the PCG Boards, local NHS Trust Boards and [redacted]. A brief summary and action plan identifying the priorities in correcting the bad points about services, and strengthening the good, will be sent to members of the public and service users who attended on the day, asking for their comments and asking for their help in monitoring the implementation of the plan. Because of the stigma which exists around mental illness, the organisers were keen that there would be no distinction between members of the public, mental health service users and professionals. At the conference and subsequent meetings, attendees used their first name – doctors and patients alike. There was no sense of the patient-doctor relationship.

A "Follow up action group" has been established to make certain that the list of key recommendations are implemented and many local people and service users are participating in this process fully. The recommendations have been fed into existing structures, plans and strategies to ensure that people get better mental health services and support mechanisms. The PCGs, mental health trust and local hospital trusts have confirmed their commitment to implementing the changes and improvements, many of which do not cost much money, and are very keen to continue working with people who use the service, or who might have caring responsibilities, or concerns about a friend or family member with mental illness. By involving the public the stigma which surrounds mental illness can disappear, the public will have more of an understanding about the various issues around mental illness and will begin to think more positively about mental health.

What was the budget for the work?

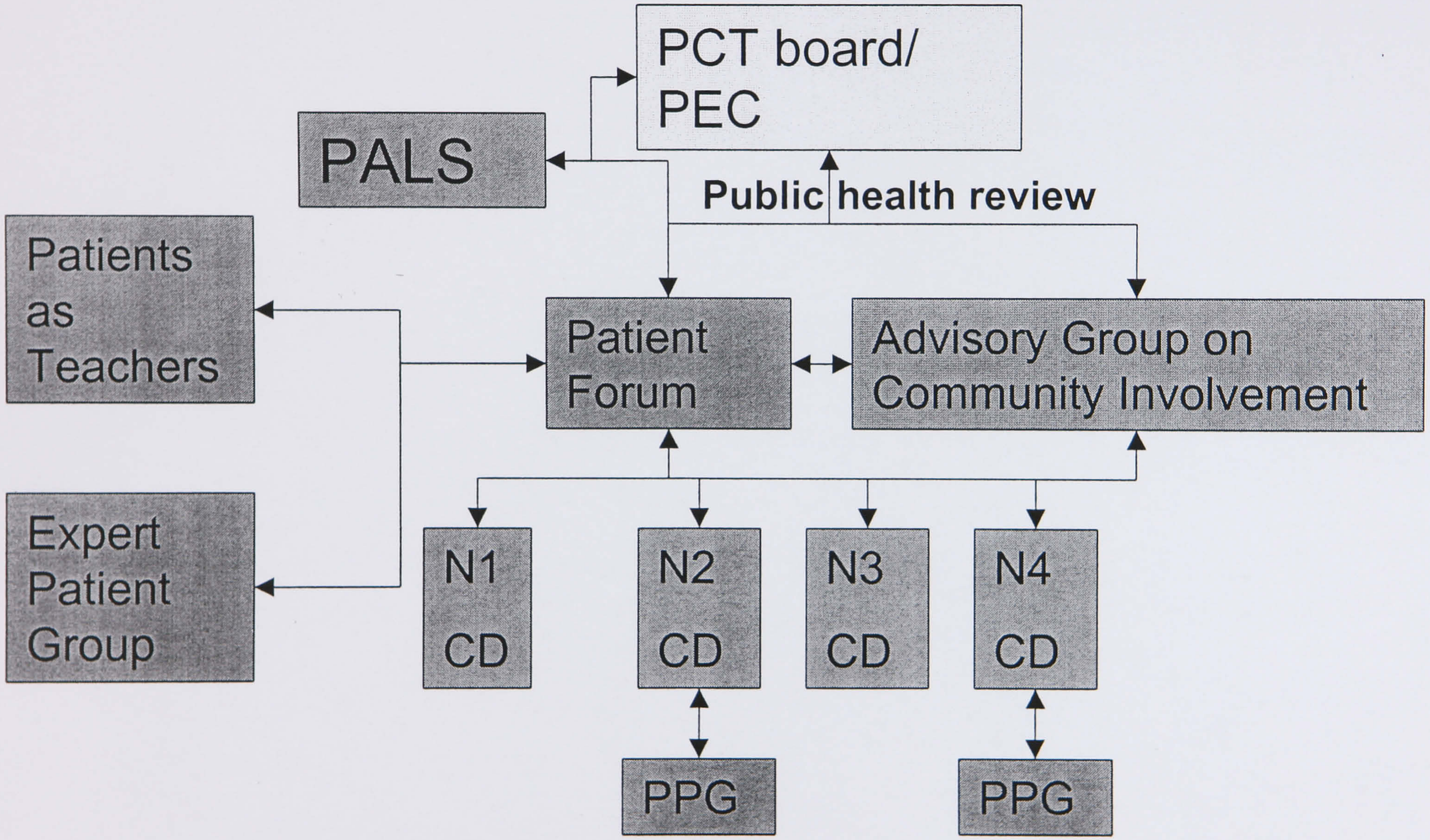
The PCG invested £6,000 in this public involvement exercise. Sponsorshiop was offered from drugs firms but was refused because of the sensitivity around medication and the effects of medication by many people with mental illness. Costs included advertising, printing posters and leaflets, postage, part-time project worker, photocopying, lunch and performing drama group.

What were the strengths of the project?

- Excellent method of involving the public and empowering service users.
- Reached out to "hard to reach" people many of whom are socially excluded
- Broke down some of the barriers, fears and anxieties surrounding mental health.
- Improved interface between all of the various public sector and voluntary bodies.
- Value for money. Sustainability. Process can be easily replicated elsewhere.
- Innovative mental health promotion at it promotes mental health in a positive way
- Service improvements as a result of involving the public

APPENDIX 17
Structure of PUI in PCT – Case Study A

Structure of PUI in [redacted] PCT



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APPENDIX 18
Job Description – Public Involvement Co-ordinator

Public Involvement Co-ordinator

1. ***Bringing a community development perspective to the user & public involvement process*:**
   - people as experts in their own health needs
   - grassroots/outreach/targeting
   - communications strategy

2. ***Key tasks:***
   - to gather existing information about the views of local people in Lewisham re. health needs & health services
   - to produce a report on public & user involvement
   - to support emerging structures- Neighbourhood Groups, Patient Participation Groups, etc.

3. ***Outcomes:***
   - a Report on Public & User Involvement
   - with proposals to mainstream local peoples' participation in the emerging PCT
   - to develop structures which reflect the real health needs of local people

APPENDIX 19
HAZ/HA Public Involvement Meeting

02 MAY 2000

Advance warning
A date for your diary

14th June, 2000

An important joint HAZ/HA Public Involvement meeting

The public involvement agenda is huge!

How can we work together to:

- share expertise and experience
- benefit from closer working
- identify gaps and potential ways of plugging them
- move the agenda forward?

If you want to join in, come along to this meeting

on

14th June, 2000

between

10.00am – 12.30pm

Followed by lunch

The Venue and further details will be sent week beginning May 8th. In the meantime feel free to contact: [redacted]

APPENDIX 20
Public Involvement Strategy – Case Study B

[redacted]PCG – Framework for Public Involvement

Draft April 2000

Module	Details	Timescale	Action by	Performance Indicators
1. PCG Board Meetings in Public	i) Publish dates and venues in advance of meetings	Year 1	[redacted]	Annual programme of meetings available
	ii) Ensure venues accessible for all attending. Loop system to be available if possible	Year1	""	
	iii) Ensure geographical spread	Year 1	"	Advertising and Communications Plan developed
1.2 Minutes of Board meetings to be available for public use, at meetings and at other times	i) Maintain file in PCG office of all papers pertaining to Board meetings ii) To offer this information in alternative formats iii) Produce glossary of terminology used by statutory bodies for use by	Year 1 Year 1	"" PCG Office Public Participation Sub Group	Have Board papers available on request Provide alternative formats for papers if requested Large print, disc, audio tape or braille if required plus e mail Glossary to be developed and available at meetings

	attendees to public meetings iv) Provide guidelines , available from [redacted]HA about Complaints Process for health service v) Have guidance on how to complain about a PCG Board meeting to be available at all public PCG meetings vi) Members to be identifiable by the general public at meetings	Year 1 Year1	[redacted]HA/[redacted] Board CEO WP JE	Leaflets to be available Produce agreed guidance Name plates to be used at all meetings by Board members Members to be introduced at each meeting
1.3 Public representation at Board Meetings	1.3.1 CHC 1.3.2 Open items for public contribution	Year 1	[redacted]CHC	Guidelines for contributions from the public developed Seek ways to improve public involvement in meetings and of topics for discussion

1.4 Involving non statutory service providers in [redacted] area	Council for Voluntary Service representatives with observer status at Board meetings	Year 1	[redacted] VAIS RAVS	List of Observers receiving agenda and minutes
2. Direct Involvement of User and Carers in the planning and evaluating of services	Programme for developing the skills of PCGs to identify users and carers views and experience of services Involve users and carers in consultations		Chair CEO [redacted] Public Participation Sub Group	Training programme for PCG Board, GP practices and PCG staff on involving users and carers in decision making about individual care or collectively about services Evidence of members of staff attending training Adoption of Carers strategy and any user strategies that may arise

3. Clinical Governance working with patients to improve the quality of service and gain better understanding of their needs		Year 2	Clinical Governance Sub Group WP	Develop a system to use complaints and comments to improve services. Using Quality Audits, Health Panels, Public Forums, Service Development Card Develop General Practice Assessment Surveys
4. Profile mapping of Surrey Thames PCG area		July 1999 – May 2000	CEO WP EL JE	Monthly meetings with specific client groups to build community profile to: i. Identify areas requiring particular focus ii. Establish key organisations and

				people providing services iii. Inform PCG of services provided by others within area Produce report and findings, with prioritised Action Plan
5. Community involvement in Health Improvement Programme Community Care and Sustainable NHS Sub Groups	5.1 Develop regular contact with external organisations , especially voluntary sector, user and patients groups, and related statutory agencies for multi agency working	Year 1 July 99 – May 2000 Ongoing June 99 - ongoing	HImP Sub Group Community Care/ Sustainable NHS Sub Group [redacted]	PCG involvement with CC and Children & Families planning groups and forums Develop a multi agency steering group to i) Develop HImP priorities and produce a plan ii) Develop a Community Care/ Sustainable NHS priority plan

Develop links with other agencies involved in HImP and Community Care work, such as Health promotion, SCC Youth agency, Social Service, Borough Councils, CHC and Voluntary Organisations	5.2 Develop chosen HImP priorities with other agencies and groups	April 99 ongoing	[redacted]	Develop Public Involvement in HImP priorities Develop Public involvement in Community Care/ Sustainable NHS priorities and develop a plan for a community development approach Implement Plan Promote implementation of HImP priorities and Community Care service developments
6. Communications with	Seek ways to	Year 1	[redacted]	Develop a

stakeholders	communicate regularly with the wider public and other stakeholders		[redacted]	communications plan and review annually. This to include newsletters, leaflets, speaking to local groups, website etc. Build relationships with key people in public domain – local councillors and MPs
7. Corporate Governance	Develop ways to inform stakeholders on role of PCG and its structure Inform all stakeholders on matter of interest resulting from PCG work and involvement	Year 1 – ongoing	CEO WP JE	Provide information on PCG role and accountability framework through Annual report and audited accounts
8. Support work of of Health Authority and other agencies	Work in Partnership with HA, BC, SSD to support projects they may undertake with regards to health aspects of citizens services	Ongoing	CEO WP JE	Identify outcome of public consultation and feedback into PCG activity, acknowledging views of users and other citizens

APPENDIX 21
Agenda Examples (Public Participation Group)

[redacted] Primary Care Group
Public Participation Group

Meeting to be held 5th January 2000 at 2.00pm at [redacted]

Agenda

1. Welcome and Apologies

2. Notes of last meeting

3. Matters Arising

   - Membership of group
   - Leaflet to promote Surrey Thames PCG

4. Public Participation Framework Development – first draft for discussion and taking forward

5. Funding of schemes for Elderly People within PCG area (ex JF monies £46K) – PCG's intentions – for information only

6. Any Other Business

7. Future Meeting Dates – to be determined

Future agenda items:

Role of the group

Please identify other possible areas of work for consideration by the group

[redacted] Primary Care Group
Public Participation Sub Group

Meeting to be held 17th February 2000
2.00pm [redacted]

Agenda

1. Welcome and Apologies
2. Notes of last meeting
3. Matters arising
4. Carer's Strategy – for information
5. Update on User participation
6. Draft Communication Strategy for Public Involvement
7. PCG Newsletter – to discuss need, target audience and purpose
8. Update of Funding for Elderly schemes
9. Any Other Business
10. Date of next meeting

APPENDIX 22
Lay Member Role Development – Case Study B

Areas of development - Ethics Register, Referral Advisory Panel & Carers Strategy

The communications manager and the lay member had developed a group with terms of reference for anyone with a problem with ethical policy. This had led to establishing a PCG Ethical Advice Panel, although had been some resistance by general practitioners relating to the involvement of the public. However, the panel consisted of PCG clinical governance lead, lay member and a PCG manager and related to a number of areas such as: - patient choice, priority treatments, equity of decision-making, pharmaceutical companies, research ethics.

A main priority for the PCG was the reduction of referrals outside the local NHS Trusts by 50%, (Annual Report 1999-2000). This was addressed by the development of a Referral Advisory Panel, operationalised in January 2000, with the lay member as a panellist. Referral requests would be subjected to a rapid review by the panel, appeals from the GP or patient was via Chair of PCG. It was assumed that referring GP's would abide by this decision, although the patient could access the NHS Complaints procedure or CHC. By contrast, this initiative incorporated formal monitoring and evaluation - the number of referrals per month, pre panel destination and the outcome of new referral process as well as the number of complaints regarding the panel. By mid April (2000), the panel had received 70 referral requests – 33% have been turned down, 33% repatriated into the local area and 33% approved. The panel, however, was slow to develop a related patient information leaflet (going to Board in February 2001). The lay member remained a member of the panel, and tested the leaflet with members of the public (Towns Women Guild) as well as the Public Participation Subgroup. In discussions in October 2001, she identified that the panel had dealt with hundreds of referrals, part of her role was to ensure, equity and an ethical way of working.

The PCG developed a set of principles for working with carers relating to a number of specific areas. Lay member had been involved in developing a carer`s group, however, again using informal networks, with the aim to raise awareness of their needs. In discussions in October 2001, the lay member identified that much of the effort was focused on GP practices rather than carers and noted the problems with practices and the

inability to inflict change – '… it was very much a GP viewpoint'. However, leaflets have been circulated to carers but with little response (Chair October 2001). Although there was an extensive carer network available, they did not take a lead in this development, and perhaps the low response is a reflection of this. However, the above work areas shows the lay member's expertise and a willingness to incorporate this into PCG developments.

APPENDIX 23
CPG Agendas

[redacted] NHS
Primary Care Group

[redacted] NHS
Primary Care Group

COMMUNITY PARTICIPATION GROUP

Tuesday, July 24th 2001 from 2:00 p.m. – 4:00 p.m.

at [redacted] PCG

[redacted]

A G E N D A

1. Minutes and Matters Arising [redacted]
2. Feedback from PCT Public & User Involvement Workstream [redacted]
3. Feedback from PCT Voluntary Sector Workstreams [redacted]
4. Comments on role of group — Enclosed
5. Have Your Say Day on Mental Health [redacted]
6. Sexual Health Provision
7. Patient Participation
8. Any Other Business
9. Agenda items for next meeting
10. Date of Next Meeting

Tuesday 25 September
2:00 – 4:00 p.m.

[redacted]

[redacted]

[redacted] Primary Care Group NHS

[redacted] Primary Care Group NHS

COMMUNITY PARTICIPATION GROUP

Tuesday, May 22nd 2001 from 2:00 p.m. – 4:00 p.m.

Room 2, Civic Suite

[redacted]

PLEASE NOTE CHANGE OF VENUE

A G E N D A

1. Minutes and Matters Arising [redacted]

2. Towards a Primary Care Trust in Lewisham
   What People Say: Voices from the Community
   Report by [redacted]

3. VAL Report (enclosed)

4. Patients Advocacy Liaison Scheme

5. Primary Care Trust Development and Consultation
   - Role of this group

6. Have Your Say Day Mental Health – report back

7. Healthy Hearts Day [redacted]

8. Any Other Business

9. Agenda Items for Next Meeting

Date of Next Meeting:
Tuesday, July 24th
from 2:00 – 4:00 p.m.

[redacted]

[redacted]

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