Have patient and public involvement forums lived up to expectations?

A qualitative study of Primary Care PPI forum groups

by

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A thesis submitted to
Keele University for the degree of
DOCTOR OF BUSINESS ADMINISTRATION
IN HEALTH PLANNING AND MANAGEMENT

Keele University
Staffordshire
March 2009

ABSTRACT

Have patient and public involvement forums lived up to expectations? A qualitative study of Primary Care PPI forum groups

This thesis investigates the establishment and operation of NHS Primary Care patient and public involvement forums and explores whether they were able to meet expectations, and fulfil their intended regulatory roles. PPI Forums, established in 2003, and now disbanded, were intended to strengthen the relationship between patient and public involvement and service improvement. This expectation of functional value was matched by a concern to also strengthen democratic process in local health policy making. To cover both lines of interest, the 'performance' of the Forums is examined in terms of their constitution, composition and mode of operation. The work is topical given the governments continuing emphasis and commitment to a patient-centred National Health Service.

The character of eight PPI forum groups in Kent is described using both survey and comparative case study approach. The survey was used to elicit basic demographic information about Forum members and to achieve access for subsequent inquiry. Lay forum members, related support organisation personnel, CPPIH managers and Primary Care professionals were all interviewed to assess their experiences, beliefs and attitudes. Further data on the operation of the Forums was also gathered through observation and documentary sources.

The study concludes that the PPI forums only had limited success. This was due to many factors, including budget constraints, confusing structures and poor recruitment processes.

There were also limitations in their roles as 'representatives' of their local communities and in working relationships with NHS professionals and their organisations.

The thesis ends by drawing lessons for groups, networks and policy makers to ensure that the experiences of lay volunteers who participate in future regulatory patient and public involvement initiatives are fully considered, understood, and embedded within local NHS policy systems.

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DEDICATION

This thesis is dedicated to the late Dennis Banks, proud at the possibility of a 'Doctor of Letters'; I owe much to your wise counsel.

ACKNOWLEDGEMENTS

After eight and a half long part-time years, this thesis has had a long gestation with many supportive people on the way. Firstly, my thanks go to Professor Stephen Cropper of Keele University who supervised the whole thesis and Doctor Sarah Derrett, who supervised a part before returning home. I owe much to your professionalism, expertise and support. Thanks are also due to my employers, all the GP partners at The College Practice, who provided some financial and practical support.

Of course, this thesis would not exist without the help and co-operation of the Kent Primary Care PPI forum group members that I surveyed, interviewed and observed. I was welcomed into your homes, but moreover you generously gave me your time as I probed your experiences of forum membership. You answered my questions with patience and understanding, and I thank you for your contribution. Likewise, the Primary Care Trust, plus former CPPIH and Forum Support Organisation personnel.

I am also grateful to all my friends, colleagues and family who, over the years, have seen every emotion possible – from enthusiasm to desperation and outright panic at various stages of this work, at least I will talk about some new project now. Particular thanks are also due to the proofreaders and helpers, Ann, Doris and Brian, who noticed the fine detail prior to printing. And finally, thank you Jemma and Colin Gilbert, who make all things possible – I truly could not have done this monster without you.

Marie Gilbert
March 2009

CHAPTER 1

INTRODUCTION

1.1 Introduction

Patient and public involvement forums have been the latest and, arguably most integrated and formalised, system for involvement of lay opinion in the planning and scrutiny of health services. This research study was concerned with the basic, yet crucial, set of understandings on which any policies for greater patient and public involvement depend.

The 1997 election of the New Labour Government brought greater emphasis on developing patient and public involvement, with a new expectation that the NHS would create advisory services and would involve patients and the public in health service decisions (Department of Health 1997). Part of the government's ongoing modernisation agenda and commitment has been concerned with finding ways in which individuals and groups, who had been excluded from decision-making, could be brought into partnership with health professionals. It emphasised that public services needed to become responsive to users and the wider public and sought to make services more accountable. It stressed the importance of citizenship as well as consumerism, responsibilities as well as rights (Baggott 2005). It also stressed the necessity for processes of collaboration and joined-up government (Newman 2001) to bring them into line with the modern world. In the discourse of modernity, globalisation had changed the economy, and public services now had to satisfy a variety of wants and needs.

This timing of this research study has been opportune in that it has coincided with a specific programme of change, which has reflected the Labour government's interest to work with the various stakeholders in the NHS, of which arguably the patients and the public are the most important, yet the least visible. The NHS Plan (Department of Health

2000) had proposed new local forums to represent patients and the public plus mechanisms for advocacy and powers for scrutiny of health services. As the researcher started the DBA programme, these new systems of involvement were mooted and then announced giving rise to questions about what this might mean in practice, particularly during a time of establishment for Primary Care organisations. Therefore, PPI forums do not sit singularly. They were introduced into a changing, and increasingly 'crowded' set of systems for scrutiny of and involvement in public services. Some had been created by public bodies to facilitate dialogue with the public at large, while others have more independent or voluntary origins. Making sense of the sheer number and range of changes in participative committees, groups and forums reflecting community views has been a challenge for public services. As Mulgan (2005) argued, it is a difficult process and can create tensions in organisations and systems, between lay person and professional, all of which contribute to confusion and suspicion.

The creation of PPI forums, therefore, seemed an ideal place in which to study the conversion of policy into action and to examine a range of lay and professional responses as policy sought to develop a more accountable and informed NHS. This thesis aims to assess what happened as PPI forums were established and started to operate. It also attempts to draw conclusions about PPI forum ability to influence patient and public involvement and considers the implications for future policy. The study therefore seeks to identify:

- The composition and profile of Primary Care PPI forums
- How the PPI forums were constituted, their activity and support
- How the PPI forums related to Primary Care Trusts and other organisations
- In what ways the PPI forums represented their communities

1.2 Research Context

Ongoing developments in government public policy have sought ways of making the health service more sensitive to the needs of patients and the public. Improved public involvement is viewed as creating improvements in the quality and legitimacy of government decisions (Barnes et al 2007). Recent government policy documents detail the benefits of patient and public involvement. It should contribute to creating citizens that are more active, manage complex problems, help build the new relationships required for 21st century governance, and develop individuals in terms of skills, confidence, ambition and vision (Mulgan 2005). Many government policies seek to encourage patient and public involvement, to make the NHS (and other public services) more responsive, inclusive and accountable (Department of Health 1999, 2000, 2001). Table 1.1, below, sets out the growing documentary emphasis, and scope of patient and public involvement.

Table 1.1 – The Growing Body of NHS Policy Documents

Year	**Policy/Document**	**Author**
1983	NHS Management Inquiry Report (Griffiths Report) *Recommended market research to establish the needs of users*	Department of Health 1983
1990 1991	The Community Care Act Patient's Charter *Patients rights made explicit for the first time*	Department of Health 1990; 1991
1992	Local Voices *Encouraged the involvement of local people within the NHS*	NHS Executive 1992
Mid 1990s	Priorities and Planning Guidance documents *These included user involvement as an objective for the NHS*	NHS Executive 1996a; 1997a
1996	Patient Partnership Strategy *Identified a need for involvement, individually and collectively*	NHS Executive 1996b
1997	The New NHS – White Paper *Outlined reforms to develop involvement*	Department of Health 1998

1998	A First Class Service *Committed the NHS to enhancing involvement and promoted close working with patients/public*	Department of Health 1998
1999	Patient and Public Involvement in the NHS *Described benefits of involvement and areas where involvement should occur*	Department of Health 1999
2000	The NHS Plan *Focussed on providing a NHS responsive to the needs of patients/public*	Department of Health 2000
2001	Bristol Royal Infirmary Report *Recommended better opportunities for patient/public involvement and access to relevant information*	Kennedy, I Prof 2001
2001	Health & Social Care Act (Section 11) *Placed duty on all NHS organisations to involve and consult*	Department of Health 2001
2003	Strengthening Accountability *Clarity that Section 11 meant changing attitudes in the NHS*	Department of Health 2003
2005	Choosing Health *Emphasised working in partnership and promoted action on inequalities*	Department of Health 2005
2006	Our Health Our Care Our Say *Emphasised commitment to changing NHS attitudes*	Department of Health 2006

In terms of the NHS, it is recognised that social change has had an impact on the way that the public views health professionals. The current NHS is a very different institution to the one first created by Bevan and the post-war planners. Their's was a system heavily dominated by those providing the service, and partnership meant the relationship between experts in medicine and the professional managers in government. Patients were the more passive recipients of care from a paternalistic service. Today many healthcare challenges relate to chronic illnesses, and evidence supports the importance of involving patients in their own treatment decisions for improved health outcomes (Coulter and Ellins 2006).

The NHS is a national institution that the majority of the public want to preserve and one that is '*there when you need it*', meaning people's expectations for the health service have risen dramatically since it was founded (Cannings 2007). However, an increasingly interested media (Doyle 2000) and increased availability of information technology, particularly the internet, has made information about health issues, illness, disease and complimentary therapies readily available to a growing number of individuals. Patient and public involvement has also risen up the political agenda in response to a number of perceived changes in civil society. Political promises, media debates and new technologies have all helped to fuel even higher expectations about what the NHS can and should deliver. Patients and the public are sometimes accused of having '*unrealistic expectations*' and policy makers difficulties in reconciling demand are frequently attributed to '*rising expectations*', with the implications that these are in some way unreasonable (Janzen et al 2005). These include a growing resistance to accepting the paternalistic styles of professionals, which have typified the health service until more recently (Thompson et al 2002) and the necessity to ensure equitable and universal health provision.

Governments have also challenged medical dominance although some authors dispute the scale of this (Johnson 1995, Harrison 1999). Some high profile inquiries in recent years, (Kennedy Report 2001, Shipman Inquiry 2001) have also highlighted the failure of some within the medical profession to live up to the standards expected by the public. The result of these factors has been for government policy makers to place patient and public involvement high on the political agenda with the ultimate aim of an open, honest, and informed approach.

Whilst the intentions of New Labour have been consistently set out, there is nonetheless, an open question about the extent to which policy would be pursued and translated into effective practice. From political science, Alford's (1975) model, although derived from studies in the United States, provides a useful lens into health policy in the United Kingdom. He identified three main structural interests in health care (health professionals, corporate planners/managers, and the community). He argued that health professionals, including the medical profession, constituted the dominant interest. The community interest, which constituted of community groups, was repressed within the institutional structure (Baggott et al 2005) unless they could exert influence by mobilising political resources. Public and consumer interests have often been characterised as lacking influence, particularly over policy (Hogg 1999, Salter 2003).

Two broad approaches, consumerist and democratic, can be distinguished within the broad discourse of involvement (Klein and New 1998, Stewart 1996, Phillips 1996). The consumerist approach emphasises the importance of '*market research*' to identify the preferences of individuals and to enhance market competitiveness. It also emphasises the rights of consumers to information, access, choice and redress in relation to products and services. Yet, the NHS has been based on the principle that scarce resources should be allocated according to need, which is a principle that would appear to be at odds with consumerism, the notion that the service should respond to consumer demands. Williams and Grant (1998) comment that people are far more than '*consumers*' when the linkages are to health related issues. Clarke et al's (2007) construction of the citizen-consumer recognises the dual or multiple practices of involvement: they point to a hybrid and hyphenated combination of citizen and consumer, each term identifying a particular and different field of relationships, identities, and practices.

The democratic approach relates to people in their capacity as ordinary citizens and taxpayers with rights to access, services and to contribute or participate with others collectively in the society in which they live. This approach emphasises equity and empowerment with participation as a key concept (Lupton et al 1998). The citizen is embodied in public identifications and practices, where the consumer is usually thought of as a more private figure. The relationship between the National Health Service (NHS) and each citizen is therefore both involved and complex as there are rights and responsibilities for each member of the public in a democratic society, but also a potential tension. Within the United Kingdom and in the context of the NHS there are many levels of democracy but there are extremes: as a participatory citizen seeking outcomes via the national elective process for their community and health service, or at the other extreme as the individual user of the service. The latter is the person with the personal focus that may wish for different outcomes than those set by national targets and policy, particularly if the issue is personal or if the issues could be life and death in nature.

Between of the extremes there are other forms of individual and community representation of interest: in the context of NHS patient and public involvement, this middle ground involves speaking and acting for others with shared, equivalent or potential interests - on health related matters. Lay representation should be important to health service practice as people who understand the outside provide a critical check to the health professional. However, it is equally important for the representative to understand the priorities of the organisation as well as the experiences of the user (Anderson et al 2002).

The NHS and its decision-making structures and processes in relation to that can appear impervious to public views, whether through representative or direct democracy. Hospital and community health services have been until recently, characterised by persistent hierarchical accountability and control by central government. Much has also subsequently been made of a '*democratic deficit*' in the NHS. The hope is (Coulter and Ellins (2006) that encouraging people to get involved in collective activity to reshape the NHS will help to reduce alienation, and promote a new sense of community engagement.

In the public policy realm, greater significance has been given to a more deliberate form of democracy (Stewart 1999), and institutionalised processes of discussion and reflection out of which can come a growing appreciation of the issues involved and of how issues should be handled in the pursuit of the '*public interest*' (Lowndes and Wilson 2001). This question of the institutional dimension of direct, democratic involvement is the central frame and focus for this study.

There is widespread recognition of the need for continued democratic innovation within public services. Compared with the NHS, public involvement and consultation processes are relatively well established in local government (Lowndes et al 1998a). As Newman (2001) and others have noted, one dimension of modernising public services has been '*democratic renewal*', in which the part played by local public services in drawing citizens back into politics has been to demonstrate not only efficient, transparent and accountable decision-making, but to broaden the range of systematically-sought, legitimate inputs into decisions. In local government, this has meant replacing the more traditional politics and committee systems with, for example, Executive Committees, Overview and Scrutiny Committees. As PPI forum policy developed, (CPPIH 2003) there were suggestions that PPI forums might feed into this structure or take on a similar status, given their intended rôle and responsibilities.

Local accountability is a common theme in government health papers (Department of Health 1999, 2002), not just upwards in the managerial hierarchy, but outwards with professionals accountable to their actual and potential patients and local people (Calnan 1997). Langton (1978) argued that the historical lack of accountability in health care was the primary reason for the formalisation of public involvement in decision-making. The government determined its policy guidance to strengthen accountability by imposing a statutory duty (Section 11) on NHS organisations (Department of Health 2001). It set out to address what the government perceived to be the major problem with the health service – a lack of openness and transparency, patients kept at arm's length by professionals, as well as the need to respond to growing public expectations of the service and to build trust and confidence within the local community.

1.3 NHS Patient and Public Involvement Forums

The intention of the PPI forums was for voluntary recruited members to play an active role in health related decision making within their communities as part of the governments overall strategy to improve patients' experiences of health services. The forums were expected to act as a vehicle for raising awareness and to represent the needs and views of patients and the public (CPPIH 2003). The PPI forums had roles and powers, like community representation, which were quite different from the former advocacy and complaints function of Community Health Councils, which, arguably, had suffered several years of declining influence (Coulter 2005).

To truly represent one's community is a tall order, and volunteers could have limited time to engage with local people, meaning there could be a balance between speaking for themselves and speaking for others. There is also a distinct difference from being a representative of a defined community (representativeness) than representing (i.e. advocating for) public/community interests. Those who speak for the community may often be formal representatives such as community workers, project leaders or local councillors, but would they always know what the people they represent think and feel?

With greater inspection rights than Community Health Councils (CHC's), including rights over GP surgeries and the private sector, PPI forums were intended to have freedom to take up issues with anyone they thought appropriate, for example local MP's, the media and a raft of local agencies (CPPIH 2003). After a long tradition of NHS organisations making their own decisions on appointing members, a fundamental change in this new process was that patients and the public were recruited to the forums independently. This independence or perceived independence of PPI forums was an important element within this research.

The previously mentioned Overview and Scrutiny Committees do have independence, even within established structures, having the ability to challenge public bodies (Centre for Public Scrutiny 2005). Scrutiny of health services by democratically elected Local Authority councillors was introduced in part to make the NHS publicly accountable and responsive to local communities (Department of Health 2003). Health scrutiny is only one part of the framework for involving patients and the public in the NHS, the other parts being the Independent Complaints Advisory Service (ICAS), Primary and NHS Trust Patient Advice and Liaison Service (PALS) and the subject of this study, Patient and Public Involvement Forums (PPI forums). However, the independence of the volunteer or lay group member has continued to have difficulty in establishing influence with local health services due to the overwhelming culture of the health professional and increasingly directive governments (Coote 2002, Greener 2003). Perhaps part of the reason is that the drivers are too weak and the incentives to achieve patient and public involvement are not strong enough.

For some time, there has been much rhetoric and interest expressed in the concept of patient and public involvement in the affairs of the State and the health service is no exception. The evolution of patient and public involvement (PPI) within healthcare reflects how involvement has now become a critical mechanism for change within the NHS. Amongst these different ways of working, it is clear there are a range of expectations from different actors – politicians, public policy makers, academics, patients, service providers and the public – about what patient and public involvement can really achieve in the NHS (Andersson et al 2006). This piece of research has sought to understand the expectations and experiences of these certain groups in order to provide insights for future policy.

1.4 Structure of Thesis

This research reports a study on the establishment and operation of Primary Care PPI forums; the study sought to determine the profile, constitution, processes and activities of a set of PPI forums; to analyse their working relationships and understanding of their mandate to represent the local community. Following this introductory chapter, the thesis is structured as follows:

Chapter 2 *Theories and Models in Patient and Public Involvement,* examines a review of literature on the main typologies, theories and concepts that have been discussed by other authors in considering patient and public involvement, including motivation and participation, democracy, representation and hierarchies.

Many political theorists have looked and identified a number of accounts of what motivates, or might motivate, participation and involvement. This is important to consider with regard to PPI forums as people joining the groups were the first necessary element.

Parry et al (1992) suggest various reasons for the impulse towards participation when discussing the primary political models or theories of participation and some of these are highlighted. Other authors (Jewkes and Murcott 1998, Salter 2003, Banks 2001) have also identified barriers in their research with regard to empowering patients and the public.

Participative, representative and deliberative forms of democracy are discussed as there are tensions, but all have strengths in a strong and healthy society. The push for patient and public involvement policies can assume that people want to engage in *'active citizenship*' or '*deliberative democracy'* and participate in health policy decisions (Redden 1999). However, this very much depends on how the public feel for their health care system beyond their own personal health perspective, how politically engaged they may wish to be, and how empowered they feel to actually have an impact (Wait and Nolte 2006). Representation, accountability and empowerment are defined separately to give some understanding of the importance, considerations and complexity surrounding patient and public involvement issues.

Conceptually and for the purposes of this study, it is important to determine what form of participation the PPI forum groups were able to establish, since Arnstein's (1969) ladder of participation, proposed a range of citizen involvement from '*no participation'* to '*citizen control*'. Many other frameworks and models for assessing the quality or meaning of involvement have been devised since Arnstein's model (Brager and Specht 1979, Byrt 1994, Charles and de Maio 1993, McFadyen and Farrington 1997, IHM 2000, Tritter and McCallum 2006), to conceptualise how patients and the public can relate to health services. There are a range of factors to consider when attempting to understand the meaning, not just the means, of involvement in policy-making processes.

Chapter 3, *Patient and Public Involvement in the NHS,* examines and reviews the increasing amount of NHS related literature. Specifically, it considers the evolution of patient and public involvement within the National Health Service since 1974, when the local statutory '*watchdogs*' – Community Health Councils (CHC's) – became operational. It is tempting to search for evidence of some deliberate design or clear sense of purpose when looking at the origins of Community Health Councils, but this would seem to be misleading. Community Health Councils were invented to fill a political vacuum, around the plans for a reorganised National Health Service, and their subsequent evolution and continued uncertainties, reflected their improvised beginning (Klein and Lewis 1976).

The system of patient and public involvement is discussed in detail, as there were many often overlapping areas to consider, together with the detailed development and changing focus of patient and public involvement forums. Forum membership was voluntary and many people were concerned to help others and to improve the quality of life not just for themselves but for the wider community too.

***Chapter 4**, Methodology,* discusses the process of conducting research design, the specification of aims, methods and choices, made about the conduct of the research, including the resolution of ethical issues. It also describes the data collection methodology and the analytical procedures used. Using a variety of methods, from documentary research, questionnaire surveys, observational methods and interview tools, the study focused on a cluster of PPI forums in one Strategic Health Authority. The chapter sets out the strategy for the study in terms of different levels of analysis which are intended to provide insight into (respectively): the characteristics of individual forum members, the characteristics of the groups themselves, and the way in which the forums were set and operated in their wider organisational and policy contexts. In each case, analysis also seeks to set expectations against actual experience.

Chapter 5, *Results – The Establishment and Constitution of the Forums* describes the main findings from the questionnaire survey and interviews conducted within the eight participating Primary Care PPI forum groups to paint a picture of their establishment, constitution and composition. Key findings are: a) that membership numbers were variable with the majority of members being over 56 years of age b) that recruitment processes were problematic and c) that forum members were unable to fully represent their communities.

The detail reported in **Chapter 6** *Results – The Process and Activity of the Forums* includes data from the interviews, and evidence from the annual report data from the first three years of forum operational activity. This chapter also examined the networking and relationships with other related organisations, in particular with the respective Primary Care Trusts, forum activity and time commitment. Key findings are a) that networking contacts were limited b) relationships with Primary Care Trusts were variable in effectiveness and c) that forum activities were limited in development.

Finally, this chapter identified some of the member expectations for the forums. PPI forums members in this study did have expectations, which could be similar to many lay people involved in health related groups. Therefore, keeping patients and the public involved and informed will be of continuing importance if expectations remain undiminished.

The final **Chapter 7** *Discussion and Conclusions* discusses themes and findings arising from the study. These are centred on a) the establishment and working practices of the forums given the limited funding and complicated structures b) the mixed relationships with the related organisations and c) the importance of understanding the representative function. Further, radical changes to patient and public involvement policy, including the demise of PPI forums after less than five years, and the proposed nature of their successor, are also documented and discussed.

This final chapter also assesses the impact of the PPI forums and their ability to influence patient and public involvement, making some suggestions about wider implications of this study and the experience of PPI forums for future policy.

CHAPTER 2

THEORIES AND MODELS IN PATIENT AND PUBLIC INVOLVEMENT

2.1 Introduction

The following examination of literature was intended to fulfil three objectives. First, to set a context for the study in an appraisal of health policy making and implementation, and in theories of representative and participatory democracy and their changing relationship to policy and practice. Second, to identify conceptual models of democratic and lay involvement in health policy, and to find a range of commentators who have explained and challenged thinking about patient and public involvement issues. Finally, to provide possible frameworks for consideration in terms of the methodology for this research. This chapter, therefore, considers a range of theories and models relevant to, or specifically about patient and public involvement, which this research on PPI forums can relate.

Organisational change has been a feature throughout the history of the NHS, but the focus has been on changing organisations and structures rather than face-to-face relationships. The pace of these changes has increased over recent years. The advent of Primary Care organisations, practice based commissioning, and the development of partnerships between health and social care have all offered changing opportunities for increased partnership and democratisation and could represent a major approach towards creating local health services (Box 2007). This has seemingly created an ideal situation for local people to work together, but the additional responsibilities associated with these new structures have also provided challenges and distractions in the battle for the provision of services.

2.2 Motives for Patient and Public Involvement

The notion of involvement and participation in health care decision-making has gained momentum (Maynard and Bloor 1998). It is important to consider what has motivated people to become involved in groups, like PPI forums, as the action of people putting themselves forward to join is the first necessary, but essential element. What would constitute a persons interest is very complex as most people have a number of interests and a number of roles, which could conflict with each other.

It is no coincidence that the interest in health care decisions have occurred at the same time as concerns have sharpened about the ability of the State to continue to fund even higher levels of service. Health care providers and managers are faced with increasingly tough and explicit choices in the allocation of resources within the health care system and it is not surprising, therefore, that they are looking to share some of the responsibility and associated pain with the public (Lomas 1997). However, does this incorporation of the public voice in decisions about health resources merely spread the blame for failures in the system and the undoubted popularity of the service? Alternatively, is there an institutional commitment to inform and involve the public in meaningful ways? Poor involvement practice creates mistrust, wastes people's time and money and can seriously undermine future attempts at engagement.

In defining political participation, Parry et al (1992) argued that participation is composed of a variety of activities. These activities differed greatly in the time and effort required, the skill and knowledge needed to perform them and the conflict they were likely to engender. Participation can be cumulative with persons who engage often being the catalyst in engaging others as well. Another hypothesis may be that different actions attract different types of people, with some prepared to engage in conflictual activities whilst others are unprepared for them. Taking this view participation and involving people takes on a multi-dimensional view. Sidney Verba first examined this in an empirical manner in 1972, looking at participation in America, which was then followed by a comparative study in seven countries (Verba, Nie and Kim 1978). Verba and colleagues distinguished between modes of participation – voting, campaigning, communal activity and particularised contacting, which occurred when people contacted a representative on matters concerned with the individual or their family. Their studies appeared to demonstrate that participatory activities had structures, which were common to different societies and cultures, and that on the whole, people tended to specialise in one or other mode of participation. However, there was no unequivocal way of ordering the modes of participation; they could not be arranged in a single hierarchy.

A number of political theorists have looked and examined accounts of what motivates, or might motivate, participation and involvement and these concepts are helpful in understanding participation in the context of the health service. Hardin (1982) stated that these motivations might be regarded as types of justification for involvement. Authors like Putnam (1993) and Verba and Nie (1992) have suggested that public involvement in decision-making can promote goals, bind people together, impart responsibility and help express civic identity. Parry, Moyser and Day (1992) suggested a number of reasons for the impulse towards participation and involvement when discussing the primary political models or theories of participation.

The instrumentalist theory is arguably the most straightforward in that participation should promote or defend the goals of participants. It is generally self-interested and in health care would be linked, in particular, to participation amongst users. Verba and Nie (1972) said, "*Participation is to us most importantly an instrumentalist activity through which citizens attempt to influence the government to act in ways the citizens prefer" (p.102).* This theory is clearly demonstrated and expressed by the governments desire to involve the public more (NHS Executive 1992, Department of Health 1999, 2001, 2003, 2005, 2006) and by users themselves (Barnes and Shadlow 1997). This perspective argued that the decision to participate resulted from a number of social forces affecting people's outlook on life and their confidence. It also looked at context, in the way people act, the issues involved, and the interests at stake.

Parry et al (1992) described a contrasting model as a rational '*economic*' theory of conduct. This model suggested that people acted in terms of assessing the value of public involvement and in terms of achieving objectives, whilst comparing this with the time and energy involved. The issue of '*why*' participate commenced with the understanding of the issues, needs and problems they face versus their economic and social interests. From this stance, the individual direct viewpoint outweighs the civic orientation to a particular need or problem, and therefore the start point for understanding involvement is with the issues, needs and interests of the individuals affected. As people's interests are, many and various there will always be a diverse range of issues. Perhaps this pattern is too simple in health as not all individuals would decide to act over a particular cause relative to them, and this may not simply be a matter of cost in terms of their time and effort.

Albert Hirschman (1970) looked at a number of economic processes, namely exit, voice and loyalty, when looking at organisations that produced outputs for customers, including those, which provided services without direct monetary counterpart. He used '*exit*' as an option for people to stop buying or being part of an organisation, based on the assumption that custom could be taken elsewhere if there was dissatisfaction with the service. '*Voice*' as an option for expressing dissatisfaction but based on the assumption that the public in the health care context are able to change the system from within and '*loyalty*' as being a concept whereby co-existence of exit and voice can be gained, and where individuals continue to '*care*' making it impossible to move away from the organisation entirely. He discussed these concepts primarily within private organisations but discusses public organisations as defined by goods '*that can be consumed by everyone, but that there is no escape from consuming them unless one were to leave the community by which they are provided'* (p.101).

Exit is the classic market mechanism for addressing provider failings. If consumers do not like a service, they can move to an alternative provider. Of course, in relating these concepts to health and the NHS, a private citizen can '*move*' from public health care by paying for private health care. However, they cannot move fundamentally, in the sense that their overall family life may still be affected by the quality of the public health service by some means or other (Hirschman 1970). To illustrate further, we could disagree with the organisation and could effectively resign as a member, but cannot necessarily stop being a member of the society in which the objectionable organisation functions. However, loss of custom acts as a stimulus for providers losing business and this structure lies behind the freedoms given to Primary Care Trusts to shift contracts or service agreements in response to unsatisfactory local services; it also underpins patient choice initiatives.

Voice is a mechanism for changing rather than escaping unsatisfactory conditions. It can take many forms, including public representation on committees, forum groups and complaints (Hirschman 1970). Therefore, one could argue that the matter is not merely an economic calculation of the likely costs and benefits of action but there is a social and ideological context as well as a personal context to involvement. Whilst recognising that there are possibilities for an individual voice in terms of advocacy and complaints, persons regularly using public services are more likely to be involved about the quality of those services if they are conscious of their collective provision and of perceived government threats to them. This consciousness would normally be a social rather than individual experience, affected by individuals in similar situations and often developed by a pressure group to raise a matter into an issue (Olsen 1971). The patient and public involvement forums described within this thesis have been one recent initiative aimed at increasing citizen '*voice*'.

The government seems to be in a quandary about precisely which mechanism it wants to drive improved NHS performance. There is currently still an overwhelming emphasis on top down management with an ongoing proliferation of centrally specified targets. Currently with the continued development of Foundation Trusts and the changing powers of Primary Care Trusts, these initiatives should be replaced by far greater reliance on bottom-up initiatives and drivers. The concept of patient exit and patient voice in the NHS could become increasingly important and is currently emphasised in the Choose and Book initiative.

Communitarian theory suggests that the justification for taking part is not found in an instrumental calculation of benefit to oneself, but rather in an identification with and concern for the community of which the person is a part. The communitarian argument emphasises the importance of social values, which will affirm the necessary interdependence of people and the role of social relationships in determining and maintaining standards of behaviour. Communitarians suggest that adequate trust must be effective between individuals, and importantly, between individuals and their social and political institutions. The concept of trust and its potential significance in addressing the challenges facing public policy is clearly becoming a part of a new language of governance in a range of settings, including with politicians (Barnes 1997).

At the centre of this theory is the view that people are integrated into their respective communities and where they strongly identify with it, involvement would be greater. Using this viewpoint people would have a detailed understanding of local needs and would share these needs within the community. In a study of democracy, Barber (1984) advocates decentralisation within communities, as the sense of community identity is greater in smaller societies. Barber explains that the low level of involvement in modern societies and communities is due to excessive centralisation and societies being remote with the result that people are not stimulated to engage in public life which appears to affect them only indirectly, or which they feel powerless to influence.

Etzioni (1996) further develops an idea of responsive communitarianism, which distances conservative communitarians, libertarians, liberals and radical individualists. In his book 'Spirit of Community' (1993) he criticised liberal arguments which place individual rights, freedoms and autonomy above the need for social order, but still eschews an authoritarian position rejecting the '*moral majority*' (Levitas 1998). Etzioni (1997) argued further that communitarianism offers a third way between anarchic individualism and repressive conformity: leaving the debate between left and right wing thinking and suggesting a third social philosophy. Etzioni also suggested that the communitarian paradigm is the '*new golden rule*', which combines individual autonomy and the common good, '*it entails a profound commitment to moral order that is basically voluntary and to a social order that is well balanced with socially secured autonomy*'. His definition of community rests not only on social interaction, but also on the function of social interaction in maintaining social control and this clearly makes the agenda one of remoralisation of social life. The emphasis on common values and civic commitment, a central communitarian theme, is bound up with the fact that exclusion undermines order. The excluded are a problem because they impose costs on the whole of society: *'those who are marginalised have less of a stake in society and its values'* (Hutton 1997).

Educative theorist views of involvement are associated with various forms of participatory democratic theory (Pateman 1970). The matter of taking part in the process of decision-making being seen as an education. This argument is, therefore, concerned with the development of citizen's competencies and responsibilities in encouraging and enhancing democracy by citizens reaching their full potential. Mill (1972) took the viewpoint that peoples knowledge increased with involvement and that this would mean a moral influence as people understood more about their fellow citizens. This concept of involvement differed from the instrumentalist argument in that although self-development is presented as a reason for participation, it is best understood as having an effect on it. It is arguable that people use involvement as a route for self-development but probably do participate initially for some instrumentalist reason, with education as a side issue (Parry 1974). Therefore, do individuals with a background in involvement develop continually in confidence or become more aware of the pertinent issues and are they likely to pursue similar action again or break new ground. This development of consciousness through involvement could become a factor influencing the potential for future involvement.

Expressive participation theory argued that individuals do not become involved to directly achieve a goal out of their concerns or those of their community, but act in order to express their feelings of political identity and belonging. Although the rhetoric of government has been '*instrumentalist*', this sense of participation as a marker of democratic renewal and civic engagement has also characterised recent political debate. In its broadest sense, this could be a form of symbolic participation (Parry et al 1992). Less symbolic would be joining a rally with other people's ideas or just the desire to be at a *'great event'* (Hardin 1982). Often the expressive and instrumentalist arguments are difficult to distinguish. By taking part and being there is an expression of solidarity and clearly registering ones presence or identity, but if there is hope of adding voice to the situation then it could then be seen from an instrumentalist perspective (Olsen 1971).

Very few theories establish effectively any clear relationship between community and involvement. Verba and Nie's study (1972) did provide some evidence but there are difficulties in the concept of '*community*' itself. What gives a community its '*quality*' is more related to the values we hold as individuals (Plant 1978). It could be expected that the arenas in which either is discussed would overlap and inform each other, particularly given that their meanings are not agreed (Jewkes and Murcott 1996). These variations in the concept of community may mean that only certain notions of community are associated with the impulse to be involved. For example, a hierarchical community may rely on its local leader for direction, where equals and neighbours seen as mutually supportive may stimulate another community. How each individual would describe a community is interesting and variable but we may all understand a community as having certain qualities and values.

The term '*citizenship*', too, can embrace many meanings. Goodin (1996) argued that citizenship is a more egalitarian concept than inclusion. Inclusion focussed on the division between insiders and outsiders, but did not address the relationship between boundaries and centre; citizenship focussed on the characteristics, which are shared. Perhaps relatively few people go beyond their localities to take public action, and therefore some appreciation of local issues and problems could shape the pattern of involvement.

Levitas (1998) looked and unpicked social exclusion and highlighted the problem of who are termed '*underclass*', often seen as single mothers, ethnic minorities or people who present society with a predicament that is morally unacceptable. The issues demonstrated that we are not living up to the professed values of a civilised society or necessarily to the government policies intended to deliver an inclusive society. The concept or meaning of exclusion refers to being shut out fully or partially and is thereby extended to incorporate inequality, therefore its converse implies much greater equality. Newman (2001) looked at a variety of governance models, and each model offered a different lens through which problems would be defined and characterised. The '*rational goal model*' tended to break down the problem of social exclusion into more manageable chunks. The government would set goals but responsibility for acting would be devolved to local or regional level, with funding linked to targets and output measures.

Finally, Putnam (2000) discussed the term social capital, which referred to connections amongst individuals and social networks and the norms of reciprocity and trustworthiness that arise from them. He argued that social capital is more powerful than civic virtue when embedded in a dense network of reciprocal social relations, indicating that a society of isolated individuals would not be necessarily rich in social capital. Putnam linked social capital with education and stated that diminished social capital had damaging consequences producing a knock-on effect in our communities. Citizen participation was also considered to be a way of maintaining social capital (Putnam 1993) and achieving a cohesive society, and as a means of reducing social exclusion (Barnes 1999a), which is fundamental in importance to health and health care. Knight et al (1998) defined social capital as essentially goodwill, sympathy, empathy and neighbourliness among the individuals and households who make up social units, whether defined by geography and/or interest. The policy reforms in the health service and local government since 1990 have been oriented towards fostering this active citizenship, overcoming social exclusion and promoting local decision-making (Hogg 2007). This '*new localism*' has aims of developing decision making within a framework of national standards (Stoker 2005).

In conclusion, there are multitudes of models and theories about what might motivate participation and involvement, and these are important to consider and understand with regard to groups, like the PPI forums in this research. There has been an increase in lay knowledge and awareness, and a general move towards forms of self-help (Olszeweski and Jones 1998). There are also increased interests in health issues due to a shift in the perception of the role of the State, including a rejection of professional dominance and a suspicion about the impact of a market economy on democracy and equity (Thompson et al 2002). The following section discusses democratic and consumerist approaches within the broad discourse of involvement.

2.3 Defining Democracy

The introductory chapter defined the two broad approaches, consumerist and democratic, associated with involvement in health. The democratic approach was primarily discussed within this thesis because the NHS system has been based on scarce resources allocated to meeting need (Klein and New 1998), as defined by the clinician or provider of the service and the overall equity principle of the NHS has required that there be equal access to treatment for equal needs. Governments have also increasingly advocated patient and public involvement as a necessary means to increase responsiveness to the legitimate expectations of the population (Wait and Nolte 2006). Public involvement is a central pillar in the health policy process in the UK (Department of Health 1999). Indeed, the Council of Europe also advocated that governments should promote policies and foster participation on the basis that the rights of patients and the public to help with determining healthcare targets was an integral part of any democratic society (Council of Europe 2000).

It is difficult, therefore, to reconcile these principles with the consumerist approach, i.e. allowing consumers to define their needs and shape the configuration of health care (Klein and New 1998). The principle of universal healthcare, based on need, free at the point of delivery regardless of ability to pay epitomised the post-war welfare ethos and became a cornerstone of British society, one which remains strong today (Andersson et al 2006). The principle of equity cannot sit well with a demand-led principle implicit in the doctrine of allowing people to define their own needs, and by so doing, shape the configuration of the health care system.

Democracy is not just an association of individuals determined to protect themselves, but a freedom in which citizens can come together to shape the world around them. Democracy is about the process of political decision-making and in terms of the NHS this is about the manner in which health decisions are taken, and what health services are to be delivered to whom and how (Klein and New 1998). Democratic forms of social organisation presuppose that citizens have a right, in equal measure, to participate in the way in which they are governed (Doyal 1997).

Political theorists, such as Parry et al (1992), defined democracy as '*government by the people*', a definition which fundamentally implies people participation. Held (1987) defined democracy as '*rule by the people*', meaning both a form of government in which the people rule, and a community in which there is some form of equality among the people. Whilst there may be scope for participatory or decision taking by the people, these are not particularly helpful definitions in all circumstances. Florin and Dixon (2004) indicate that greater public involvement will lead to more democratic decision making and in turn enhanced accountability. As indicated in Chapter 1, democracy in this context relates to people in their capacity as citizens and taxpayers with rights to use public services and duties to contribute to and participate in society (Lupton et al 1997).

In its broadest sense, there is general agreement that those governed should elect decision makers. However, many dictatorships are elected and one could argue that the vital condition for democracy to exist is that the decision makers should be answerable, and that if they fail to satisfy, they can be removed. This still does not give protection however, against any abuse of power by those given a temporary license to rule.

In defining the criteria necessary for democracy within the context of the NHS, the first inevitably must be that the decision makers are accountable to the governed, this being accountability in the strong sense (Klein and New 1998). This demands sanctions if the decision makers fail to satisfy or give a convincing account of their conduct. There is also accountability in the soft sense, which is the requirement to justify performance with the governed making the decision makers answer for their actions. This in turn means that the process must be transparent and that there should be a free flow of information.

Secondly, the processes and structures of decision-making should be permeable and should allow opportunities for the governed to express their views and to influence the outcome (Klein 1998). From this perspective, democracy is all about the dialogue and any mandate needs keeping under review with testing for acceptability along the way. The emphasis should be on accessibility and visibility in policy-making, meaning most of the decision-making processes undertaken in public and the reasons for the decisions published more extensively. Aided by the media this would allow more public scrutiny although increased openness could equally cause difficulties with pressure groups (New 1997). Thirdly, the actions of the decision makers must conform to rules of conduct designed to ensure equity in the treatment of citizens, that they reflect the power of the law with decisions made after full consideration of all the evidence (Klein and New 1998).

Blaug (2002) discussed two competing discourses about democracy. Incumbent democracy is described as liberal, realist, representative, institutional and protective. Public involvement is viewed through market values, as a competition for votes and the political survival of the fittest. Hindess (2000) commented that incumbent democracy is concerned with falling levels of involvement, which are a concern because they threaten the quality and legitimacy of elite decision-making. Involvement in incumbent democracy is characterised largely by voting, by interaction between structured groups and by orderly civic involvement. The strengths of this form of democracy lie in its effectiveness, and its ability to command resources centrally, the stability it offers to individuals and its perception as being conducive to economic growth. Incumbent democracy is primarily motivated to preserve and improve existing institutions by maximising and managing orderly involvement.

Critical democracy (Blaug 2002) on the other hand is a response to suffering and injustice. Involvement is characterised through primarily deliberative, direct, developmental and personal means. It means resistance to elite governance and is characterised by increased involvement and empowerment. It is generally face to face, with decision-making preceded by open augmentation and debate typically seen in civil disputes. Critical democracy would seek to resist any management and would seek to empower excluded voices in such a way as to directly challenge existing institutions. Both have negative sides, incumbent democracy could degenerate into competitive elitism, a political form with no legitimacy. Critical democracy could appear disinterested in the realities of politics, disorganised and ineffective (Blaug 2000).

There are other theories about how involvement can supplement or fundamentally change representative democracy with new roles for citizens, the state and civil society. Part of the problem, between participative and representative democracy is the lack of mutual understanding and clear systems to link the two, although both have vital strengths Representative democracy creates very clear lines of accountability, so that when things go wrong it is clear where the buck stops. This is often not the case for participative or direct initiatives, which are often used to undermine clear accountability by undermining the results of a participatory process with a view to using it as a scapegoat should the decision be problematic or ignoring the results of the process, depending on which is more politically expedient (Mulgan 2005). Saward (2003) identified the learning in enacting democracy and several well-established ideas and practices of representative democracy, including the distinction between '*direct*' and '*representative*' democracy.

There are, however, significant developments towards a more deliberate form of democracy, particularly in local government, meaning a process of discussion and reflection out of which can grow an appreciation of the issues involved and of how issues should be handled (Stewart 1999). Elster (1998) suggests that voting alone produces decisions that are inferior to those reached after dialogue and deliberation, and the benefits of deliberate democracy are precisely those which governments interested in *'social capital'* might seek.

Patient and public involvement forums were designed somewhat to provide a more deliberate form of citizen approach. The ideal and the necessary emphasis is, however, for a shared arena so there can be a supportive two-way discussion but problems remain in the limits of the NHS institutional framework and processes that often appear impervious to public views. Authors like Alford (1975) and North (1995), have commented on the professional dominance within the health care system and the wide acceptance of professional status and knowledge meaning repression of the community interest. When Primary Care Trusts were first put in place there was a modest emphasis on improving aspects of local service delivery by, according to the NHS Plan, '*giving local health professionals more freedom to develop new services by bringing together in a single* *organisation primary and community care services'* (Department of Health 2000 p.57). However, there has been a vast increase in the scope and importance of their functions since their creation and the successful delivery of many government targets and strategies for NHS reform. These include patient choice, payment by results and practice based commissioning (Department of Health 2005).

In a discussion on democracy, the starting point is the way the service runs from the centre. However, if the notion of the health service is to be taken at face value, there should be no difference or discretion allowed to any organisation; the same package of health care should be delivered to the same standard everywhere. In practice variation within the NHS remains the norm, only justified on the basis that national policies are adapted to local circumstances (Klein and New 1998). Throughout its history, the NHS has never resolved this ambiguity, and there has been a recurring cycle of devolving responsibility followed by a return to centralisation.

It is essential to allow development of local ideas and to encourage innovation directly in contrast with the centralised democracy, which is rigid and conservative (Phillips 1996). If involvement is the key then it is not difficult to see why more centralised systems of democracy make matters harder to achieve. Local democracy may be the best means of enhancing democracy itself: by making it easier for people to be involved and responding to the particular needs of different communities. The main point however must be that more localised democracy can challenge the actions of the centre, and current NHS reforms reinforce locality as a key basis for involvement (Andersson et al 2006). There would however, be cost factors in achieving local democracy. The type of person to recruit may also be in short supply and may require certain expertise or potential to fulfil the role.

The second point to note is that the professionals managing and delivering health care are not employed by the Secretary of State but by a respective Trust, meaning no line of disciplinary action (Klein and New 1998). The doctrine of professional autonomy also means that Doctors are not accountable for the way in which they use public funds. In conclusion, the NHS has a line of accountability running in theory directly from the point of service delivery to the Secretary of State, although the Minister does not directly control those who are responsible for the care of patients.

Another characteristic of a democratic society is that individual citizens should have the opportunity to seek redress if they feel aggrieved at, or oppressed by, the actions of those carrying out the tasks of government (Klein and New 1998). The NHS has had an elaborate complaints system since 1996, which all Authorities, Trusts and general practitioners have to operate but the fundamental issue is more about how to influence, make a difference and work in partnership to improve the patient pathway and experience.

The other crucial factor for consideration is the objective of fairness. Any democratic decision may not sit comfortably with us with our sense of social justice – and our sense of belonging to a wider community (Lenaghan 1997). We would all want a fair society where we have equal treatment and few of us would argue that a *'relevant'* difference is our postcode, or one's place of residence. Although, if we pursue greater local democracy, unreasonable and unacceptable variations may be legitimised and inequity must remind us that democracy in general, is not the only goal of modern societies (Klein and New 1998).

Clarke et al (2007) emphasised the changing role of the citizen and discussed the concept of the citizen-consumer. The transformation of citizens into consumers diminishes the collective ethos and practices of the public domain and both privatises and individualises them. Clarke emphasises that the publicness of the NHS can dominate concerns about the future and the idea of a collective, inclusive public resource still commands attention in ways that consumerist choices cannot. The overarching principles of the NHS were strongly voiced within this research study and there was discussion on relevant terminology and its importance when relating to health matters.

To conclude, democracy is an essentially political concept. It is about the process for making decisions about how collective power should be exercised (Klein and New 1998). However, this simple definition masks a complex set of concepts and possibilities for the design and organisation of democratic engagement in public affairs, including the governance of public services. The NHS is often characterised as having a democratic deficit, and the development of a range of measures to enable '*voice*', and the introduction of consumerist mechanisms of '*choice*', including '*exit*', might be seen as responses – on the one hand to citizens and on the other hand to consumers – to that critique. In delivering the full NHS Plan, it is important to understand the forms of democratic device that are introduced, and to ensure that the right structures are in place. Thinking through how exit and voice can work together is crucial, particularly as the picture will be more complicated by audit, inspection and scrutiny hovering in '*top down*' mode. If new health agendas, like '*Choice*' are going to be the ultimate measure of democracy within the health service, then there would have to be a change in the fundamental principles of the NHS and its origins built on an ethos of community spirit, solidarity and sharing.

2.4 The Importance of Representation, Accountability and Empowerment

2.4.1 Representation

The question of representation is an important element to consider within this research study. The NHS does not, except through the general election process, follow a traditional representative democratic model of involvement: rather the engagement of public and patients is through mass communication with appointed lay members identified as representatives of consumers and citizens. The PPI forum group members were required, within a range of responsibilities, to play an active direct role in representing patients and the public in the planning and scrutiny of health services, as documented in their forum member reference guide (CPPIH 2003) and as stated in the government Statutory Regulations No. 2123 (2003). What then, is the nature of the representative role?

Representation is defined in relational and essentially political terms as:
'always of something or someone, by something or someone, to someone' (Mitchell 1990).

Representation could be an active direct relationship between the representative and those represented rather than the more common passive indirect process. However, a direct process implies participatory democracy, in which the elected represent the views of the electorate with the representative seeking to balance different views. The meaning of direct involvement in this context would be people playing a part in making decisions, and indirect involvement is people used as a source of information, ideas and experience.
Do we really understand the true nature of representation? The public are somewhat confused on the meaning of representation, and of its relevance in their lives. Members of

the public appear to fall into one of three camps according to their perception of representation and its effectiveness. A study by the National Consumer Council (2002) found the following patterns:

- activists – are a vocal minority who are committed to the concept but object to the practices that can exploit them as consumers/public. They often have long histories of complaint, largely on principle
- fatalists – this group recognised that consumer rights are important but also argued that people are naïve in expecting representation to work, or organisations to take notice of consumers/public views
- outsiders – this group comprised of mainly younger, ethnic minority and socially excluded people, feeling that representation was just one of many areas where they felt excluded

The notion of representing others can be a difficult concept and there are common concerns about the particular pool from which recruitment of representatives are drawn. An individual may be considered a community representative, possibly in terms of ethnicity, but do they truly represent their local population as a whole? Equally, are they the right person in understanding the interests of a particular section of the community i.e. young people? Finally, is there importance in having representativeness or ethnic balance within any group claiming to represent others? Other parameters chosen as monitors, for example ethnic minorities or women, fail to include other basic categories as the elderly or the young and, in particular, the elderly are principal users of the NHS. If representation were weighted towards the majority who use the service then older people and children would need high representation.

As indicated in Chapter 1 (page 10), there is a difference from being representative of a defined community (representativeness) than representing (i.e. advocating for) public/community interests. Often the active citizens who speak for the community are generally the better off or better educated, but are they representative of all the community? People who are poor or disadvantaged (i.e. those likely to benefit from public involvement approaches), may not be represented at any stage. In the case of PPI forums, were members appointed to represent patients or the public and is there a difference? If members are only representatives of the wider public, should they be more representative and reflect ethnicity, education, social class and demographic factors, as suggested by Klein and Lewis (1976) and more recently by Hogg (2007). Dovi (2002) discussed the criteria of '*descriptive representatives*', classed as historically disadvantaged groups, who are represented by members of their own groups. Dovi argued that some descriptive representatives are preferable to others, and criteria for selection were important, so that descriptive representatives possessed strong mutual relationships with dispossessed groups.

The task of trying to ensure '*representativeness*' in any forum or group may always be difficult and problematic. Conceptually, the commonality of experience or identity may actually facilitate more discussion and produce a greater depth of understanding than a more representative sample may elicit (Newman 2001). A further difficulty is that many patient or public involvement initiatives are locality-based and assume a commonality of interest and identity based upon residence within (or some other affiliation to) that given community area. In this scenario, differences of interest and identity or economic position could be dissolved into a more inclusive orientation, particularly when common purposes, supportive relationships and regular leadership are adopted. Like the PPI Forums, some community groups are engaged in dialogue and have some, albeit differing, forms of power. These communitarian concepts have certainly been highlighted by the Labour government in some policy documents and have provided a recurrent reference point, see also Chapter 3, from page 90.

One key question concerns the '*mix*' of members within any representative forum and the relationship between that '*mix*' to the population represented. A common-sense political expectation would be of equivalence, the forum matching variety within the population. Lowdnes et al (1998a, 2001) concluded however, in extensive research within local government, that it might actually be unrealistic to seek *'balance'* within each type of forum or group setting. There may be a need to use incentives to engage those who would not normally take part. There may also be a dilemma in encouraging and motivating people to participate and building on the competencies of those willing to be involved, and on the other hand continually widening the process to include new participants. Realistically, long-term development of confidence and trust of traditionally excluded groups would be important and necessary, and citizen education from school onwards may be a factor in changing the attitudes of *'those who dominate'* (Lowndes et al 1998b). Gaffney (2002) noted in her study of unpaid community workers, that there was a strong adherence and importance of working with community members and that there was an overall idealism about community involvement that was clear and distinct from personal motivations.

When we represent others in a discourse or conversation, particularly in a formal context and where '*important*' issues are to be discussed, our relevant experience would be one criterion for our inclusion in the discussion (Little et al 2002). However, experience can potentially restrain us, as the nature of our experience informs what we say but can limit our legitimacy and power. To put this in context, a public representative or expert patient who has experienced a serious illness like cancer could be a good choice as part of a cancer or Expert Patient group although these initiatives appear to have varying degrees of success nationally. However, these representatives have to interact with professionals who have extensive clinical experience and who understand financial and ethical implications. The representative comments, although valid, may seem out of place against the statistical, pooled experiences. Alford (1975) commented on the dominant interest of the professionals, and in particular the medical profession.

The Commission for Patient and Public Involvement in Health was expected to have a much wider role than simply setting up and managing the forums, it was intended to promote patient and public involvement in the NHS and be a national voice. However, pressure to set up the Forums quickly meant that the Commission was expected to perform and function before it had chance to reflect on the nature of its role or to establish its vision for the future. As indicated further (in Chapter 5), the Regulations (NHS Statutory Instrument 2003), also specifically stated the criteria for PPI forum membership. The PPI forum system was charged with representing patients and the local community in the planning and scrutiny of local health services. The statutory documents (2003) carry this through into the definition of roles for forum members. However, how realistic is it to expect representation from unelected volunteers who may have had no previous experience in health or indeed the voluntary sector. There were also distinct choices made in limiting the boundaries of representation by creating some exclusion's to forum membership (NHS Statutory Instrument 2003). As examples, no person working within the health service could be appointed to a forum in their work area and the age limit was set at eighteen upwards, excluding younger persons. Pre-designed exclusions in this way are unhelpful in encouraging and fostering volunteer memberships.

In the context of a PPI forum, representation meant that the forum member voiced the community perspective and took part in the decision making process on behalf of that community. Individuals taking part in focussed discourses are there to represent the interests of people like themselves. While individual or personal experience may be helpful, the principles of representation are important, because they apply equally to each participant. The voice of individual experience is more likely to be heard when it speaks on behalf of others who have had similar experiences (Little et al 2002). The question of who to involve can often be complicated, as everyone has a special interest in personal health and that of immediate families but, often, anxiety about whether a person is fully representative can seriously inhibit public involvement work. Any choices regarding whom to involve necessarily means choosing whom not to involve – and such choices can also be unrepresentative (Anderson et al 2002).

Within the voluntary sector, organisations have developed mechanisms of representation often feeling that they can speak on behalf of their membership on particular issues, although many aim only to provide an information exchange and to support members and facilitate citizen participation in the decision-making process. Even if organisations do not feel they represent individuals, the work completed is informed by the experiences and opinions of individual patients (Thompson et al 2002). Voluntary organisations have their roots in civil society, in citizens coming together to make a difference to their lives, their community or to the lives of others, independently of both the state and the market (Pratten 2006).

The fundamental issue is what you want your representative for, as all else really flows from what you are trying to achieve and the role you want your representative to perform. The real value of representatives lies in their necessity to identify public need, and to champion the interests of others and to put their side of the argument. Representatives can be appointed due to their expertise, experience and knowledge in the subject area or their ability to feed in expert views (National Consumer Council 2002). There obviously has to be a clear approach on what individuals and groups can expect to achieve and clear guidance on the expected or anticipated roles. These fundamental points were important in respect of PPI forums, particularly around the recruitment procedures and person specification, which together ultimately and arguably, could affect forum success.

Primary Care Trust boards are constituted with elected members but there are few questions about whether a PCT Board general practitioner (GP) is able to represent the views of all GPs in the locality. They cannot fully represent, but there is an acceptance that they have put themselves forward to make a difference to their locality. The only difference being that the elected members are defined as professionals rather than the voluntary member perception, with a general lack of health knowledge and experience. The anomaly of being a representative may at best encourage the development of inappropriate health care services, but worse perpetuate inequalities of health within the population (Freeman et al 1997).

To conclude, for fifty years or more paternalistic traditions in the NHS have confronted patients and the public with a deep rooted '*take it or leave it*' mentality because care was provided apparently free at the point of use (despite payments via tax). However, those days have changed and the culture needs to move on and work closely and collaboratively with patients and the public towards a point where people can challenge, can have more control of their health needs and can articulate this directly with the NHS (Pickin et al 2002). The pressures on health care systems are intensifying, as public expectations and scientific advance combine and test their capacity to cope (Woods 2002). The importance of health to patients and the public also places those who govern under scrutiny and the result has been new ways of demonstrating performance, including legislation (Department of Health 2001), to extract continually higher levels of performance.

For patient and public involvement to have an impact on health services, health organisations need to continually improve communication about health care needs, services and policy choices, and that they aspire to ensure that everybody who wants to influence the improvement of services, actually have the opportunity and support to engage. There is a legal duty to involve and consult (Department of Health 2001, 2007), and this duty has also required consultation with PPI forums and Health Overview and Scrutiny Committees, from the beginning of any process leading to '*substantial variation*' in health services (Department of Health 2007). This definition of '*substantial variation*' is somewhat difficult to determine but needs to take account of accessibility, the impact of service change to the wider community and other services, and the proposed methods of service delivery.

As indicated later in this chapter, a more realistic model of involvement is necessary, which is relevant to people at different stages of their lives, and one that is not reliant on the dichotomy of representative versus other. Tritter and McCullum (2006) discuss the potential richness and complexity of democratic engagement with health policy. They note possibilities for connection of a multiplicity of individuals and groups, and the integration of both one-off and more continuous involvement – no one size fits all. The outcome they propose is one that enables and articulates the potential involvement of diverse members of a multi-cultural society in informed debates about a complex, and constantly changing system like the health service.

2.4.2 Accountability

Accountability is commonly understood to mean the giving of an explanation for the discharge of responsibilities entrusted to individuals or organisations, in short a justification of their conduct. Accountability is a fundamental component of governance, which requires a process for judging the performance of the '*governors*' by the '*governed'*. This has the implication that some form of performance measurement, however basic, must inform the exercise. There are implied needs also for the actions of those being held to account to be open to scrutiny and for those making the judgements to have the powers to cross-examine and have access to information to assist the process (Woods 2002). Accountability is related to democracy, as the governed have periodically required a reckoning from their political leaders and have had the option to dispense with their services if found wanting (Klein and New 1998).

The Nolan Committee, in its first report (Standards in Public Life, 1995) defined accountability, which is identified as one of its seven basic principles of public life, in these terms: '*holder's of public office are accountable for their decisions and actions to the public and must submit themselves to whatever scrutiny is appropriate to their office'*. The roots of accountability are in the keeping of financial accounts and although an important component, it is only one part, others having emerged to complement the original meaning (Woods 2002). Over time, this has meant that the word is used in diverse and changing contexts, which conveys particular meanings to individuals dependent on the time and place. The key to the process of accountability is the way in which information is provided, directly and indirectly, to the different stakeholders who have a legitimate interest. In the context of public services, accountability is defined as *'the obligation of those entrusted with particular responsibilities to present an account of, and answer for, their execution'* (OECD 2005). Accountability is ensured through systems of control, which are defined as *'processes designed to provide reasonable assurance regarding the effectiveness and efficiency of operations, reliability of reporting and compliance with law and regulations'* (OECD 2005). Ashworth and Skelcher (2005) identified these two dimensions of presenting an account of and answering for even further when reviewing local government modernisation. They identified four components of accountability: taking into account, giving an account, holding to account and the right to redress.

Unsurprisingly, there are calls for greater openness in the decision-making processes of NHS organisations. Day and Klein (1987) also studied accountability in five UK public services, including the health service, and described the word as *'a slippery and ambiguous term'*. Mulgan (2000) referred to the expanding nature of the concept beyond the 'core' purpose of being called to account. New (1993) looking at accountability within NHS organisations from a theoretical perspective distinguished between political accountability – the relationship between the governed and those who govern and administrative accountability – the means whereby those who govern are held to account (Woods 2002). In practice, it has been difficult to categorise accountability as there are connections that overlap and public management has been characterised by the need to work with multiple accountabilities (Polidano 1998).

Political accountabilities are a fundamental feature of democratic government. In terms of health services within the United Kingdom, political responsibility rests ultimately with elected politicians who are held to account for their stewardship of their responsibilities by the public at periodic elections. The NHS is unique, and based within one of few countries that remain predominantly funded out of general taxation, having direct responsibility of central government. It could be argued that this method of funding has determined the line of accountability, and as the NHS is funded out of general taxation, the Secretary of State has remained answerable to Parliament for the way in which the public money is spent (Layfield Committee 1976). Therefore, in turn, because the Secretary of State is answerable to Parliament, he or she cannot avoid responsibility for the running of the NHS. A consequence of centralised political accountabilities are often accusations of a '*democratic deficit*' (see also Chapter 1, page 8), particularly when there are unpopular proposals for change made by NHS organisations. Centralised political accountability is often perceived as remote and ineffective and can lead to confusion (Powell 1998).

Administrative accountability is concerned with the agencies and individuals responsible for implementing decisions of law making bodies (New 1993). It has remained complicated to separate from political accountabilities in the NHS as the minister's principal advisers (NHS Chief Executive) have responsibilities in legislation for the activities of NHS organisations (Woods 2002). The government paper, Shifting the Balance of Power (Department of Health 2001) had the objective of shifting the decision-making power down the NHS structure, in an attempt to lessen the control from the Department of Health. Ultimately, this resulted in Strategic Health Authorities, Foundation Trusts (see also from page 130) and the Primary Care Trust structure.

Both political and administrative accountability are of great and growing importance in health care systems, particularly around the involvement of patients and the public in the activities of NHS organisations. Alford (1975) analysed the distribution of power between interest groups and identifies that accountability is about the control of power and those who exercise it, with '*repressed interest*' typified by communities without influence in health care systems. North et al (2001) highlighted the continual weakness of the community despite the emphasis of patient and public involvement.

On the provider side, new forms of local accountability have been required for NHS Foundation Trusts since 2004. By contrast, Primary Care Trust (PCT) commissioners remain accountable largely upwards via the Strategic Health Authorities to the Secretary of State for Health and ultimately parliament. Although PCT's upward accountability systems are still in place, the fundamental question is whether local accountability needs to be enhanced. The absence of downward accountability from PCTs has being called into question by some Labour government ministers (Evans 2007), and the opposition parties. Hazel Blears said, *"PCTs hold a huge power over our lives, yet we have no direct say over them*" (Blears 2007). The Liberal Democrats argued that people had 'no effective control over their health services' (Lamb 2007) and the Conservatives proposed much closer links between PCTs and local government to address the gap (Conservative Party 2007).

Primary Care Trust roles are constantly changing, and becoming more complex and powerful, not least in holding large budgets, allocating resources and contracting with providers. It is perhaps not unsurprising; therefore, that achieving local accountability in the NHS is an important and ongoing objective for government. The calls for greater accountability appear to be aimed at resolving problems, like the perceived lack of responsiveness to the views of local people and the lack of legitimacy in PCT decision-making (Thorlby et al 2008). In reviewing PCT accountability, there is a much wider debate about how to increase local engagement. These include using new forms of participation to build social capital and create healthier communities through civil renewal (Stoker 2005). Delivering local accountability may always be challenging for two reasons: the unwillingness of enough members of the public to be involved to mount a serious challenge to decision-making, and the unwillingness of NHS institutions to change in response to challenge.

The pursuit for perfect accountability may also increase the provision of information, more comparisons and complaints, with the dangers of building a continuing culture of suspicion, low morale and ultimately cynicism. It would be unsatisfactory to simply standardise a service and to measure this by a set of performance indicators. However, people who are called to account should give a full report highlighting their successes and failures, and directed to people who can independently judge how institutions or professionals work. There is no doubt that many factors affect local implementation. These include the local political landscape; conflicts between national policies and local priorities; the strength of strategic and operational partnership arrangements between local authorities and the NHS; and the existing accountability arrangements of each sector, to both local people and central government.

In terms of patient and public involvement forums, accountability was linked to scrutiny of the service, and legislation had reformed the framework for involvement. Apart from the Section 11 duty in the Health and Social Care Act (Department of Health 2001), there was also the introduction of Local Authority scrutiny on health and a requirement for NHS bodies to consult health Overview and Scrutiny Committees about major changes. Scrutiny in this health context is about holding others to account and scrutinising the work of the health provider when it affects the well-being of the local population. This scrutiny is different to the involvement and voice of the patient and public involvement forums, the main difference being the level of power and wide ranging responsibility, and the ability of Overview and Scrutiny Committees to make recommendations and hold NHS bodies to account and refer to the Secretary of State, where appropriate (Martin 2006). Primary Care PPI forums did have the ability, however, to refer relevant matters to Overview and Scrutiny Committees.

Annual reports and reviews are another means of looking at accountability but only if they are comprehensive, widely available and actively involve representatives in their preparation. In terms of the PPI forum group accountability and from the Forum Regulations (CPPIH 2003), mechanisms of annual reporting were required. Each group had to publish and circulate a report describing their activities and work including the methods used to obtain local views. Forums were also required to report back to their respective communities, '*to let people know what happened as a result of giving their views and how the forum acted on them*' (CPPIH 2003, p.21).

Transparency and openness are key components of fair process so that everyone can accept that health matters have been fairly met. However, fair processes must also be empirically feasible. They must involve practices that are sustainable and that connect well with the goals of a variety of stakeholders in the institutional settings where these decisions are made. Singer et al (2000) pointed to key elements of the decision making processes that could be further improved to achieve legitimacy and fairness, namely that of fair process. Fair process requires publicity about the reasons and rationales that play a part in decision-making, as people should not be expected to accept decisions that affect their own well-being unless they are fully aware of the reason for that decision.

Often the media and activists invoke a supposed public '*right to know*' on all matters. Freedom of information has become the admired ideal and openness and transparency are often seen as this ideal (BBC Reith Lectures 2002). It is interesting to reflect that these high ideals have done little to build or restore public trust. Perhaps more difficulties lie around our media freedom with a press having almost unaccountable power. The image of a free press speaking the truth or with reporting that we can access and check seems inconceivable, but vital.

In the context of the NHS, perhaps we are in the grip of a deepening crisis of public trust and have little defined accountability but are current levels greater than those of the past? Evidence has suggested that recommendations by local people can improve the style and quality of health services (Farrell 2004). Some NHS organisations have developed mechanisms to hear local views in aspects of care, but these are not systematised and are not very effective (CHI 2004). Although government legislation, like Section 11 (Department of Health 2001) has ensured NHS organisations seek out views, there are no guarantees that these will be acted on (Fisher 2006). There may not be the evidence of a crisis but there is massive evidence of a culture of suspicion, often surrounding government policies. Linking this thought again into what we are endeavouring to build in patient and public involvement begs the question that we could be damaging matters rather than supporting them. Plants cannot flourish if we pull them up constantly to check their roots are growing or constantly uproot to change and reconfigure, as in the case of PPI forums.

In conclusion, perhaps the two elements of accountability and trust are interwoven around the notion of empowering others (BBC Reith Lectures 2002). There are aspirations and attempts to make public servants more accountable in many ways to more stakeholders, but can this revolution in accountability remedy any crisis of trust? Since trust has to be placed without guarantees and particularly so in the health field, it is inevitably sometimes misplaced. It is valuable social capital and should not be squandered, but recognised that we need to place trust with care. When trust and confidence between parties in an accountability exchange are broken there is only one outcome, and the day of reckoning will have arrived (Woods 2002). The extent to which accountability structures inspire confidence and trust will determine their ultimate success.

2.4.3 Empowerment

The idea of '*empowering*' patients and the public has been an important feature of government rhetoric for some years, and was a crucial dimension in the Labour government's effort to forge a fresh approach to social policy (Coote and Ellins 2006). A crucial element is to encourage individuals and groups to help each other and themselves, building reciprocal relationships that help to glue communities together. Empowerment has been defined as '*a social action process in which people and communities gain mastery and control over their lives*' (Wallerstein 1999, p.40).

Empowerment is a process of increasing personal, interpersonal or political power so that individuals, families and communities can take action or voice opinions to improve their situations (Holosko et al 2001). Empowerment involves individuals increasing their ability to take effective action on their own behalf (Meade and Carter 1990) or via assistance from other groups. This definition has a number of components. First, empowerment could be defined with reference to the pre-existing behaviour of particular individuals or groups, in other words it is both subjective and relative. It could be something the individual or group may not have done before and one, which they believe, will advance their interests. For some, empowerment may be asking a question at a public meeting, while for others this may be a pursuit of a court case. Empowerment is then a process through which individuals and groups go and results in them having a wider choice about how to act (Skelcher 1993). Empowerment is also about effective action and making a difference to the lives of those who decide to act. Jewkes and Murcott (1998) discussed barriers that can affect empowerment and highlighted the problem of engaging with and empowering '*hard to reach*' groups.

What determines an individual to become empowered to express their feelings is somewhat debatable. In the quest for empowerment there are many who doubt the value of '*top down*' prescriptive policies generated by governments or health professionals and suggest that the initiatives extolling the views of the population, should emerge from the communities themselves (Calnan 1997). Apart from the PPI forums, there are groups that have emerged from social movements, which have aimed to provide support and information for the health service user and act as a pressure group sometimes challenging professional models of health care. There are also community projects resourced by Local Authorities and governments in an attempt to facilitate empowerment and social change, particularly in the context of New Labour's '*democratic renewal*' agenda and as the result of longer-term processes of innovation in local government (Lowndes et al 2001).

Gutierrez (1994) said, *'Empowerment involves the process of increasing personal, interpersonal or political power so that individuals, families and communities can take action to improve their situations'* (p.232). At the individual level, empowerment is related to feelings of mastery, competence and personal power (Breton 1994, Miley et al 1998). According to Gutierrez (1995) knowledge, communication skills, appearance and the roles of individuals all affect their experiences of social power. Access to resources and the opportunity to shape those resources are central components of community level empowerment (Hasenfeld 1987). Collaboration and partnerships are identified as hallmark components of empowerment (Miley et al 1998). Tower (1994) encouraged agencies to foster active consumer input into goals and policies, and practitioners to align themselves with the interests of consumers.

Disempowerment, which was introduced by Kane and Montgomery (1998), refers to the process that unfolds when an individual perceives a lack of respect for his or her dignity and voice. Disempowerment occurs when there is acceptance of a principle of involvement, but moral ambiguity toward it. To have included a lay representative in a policy making committee is to signal recognition of the discourse of individual experience, but that discourse does not sit comfortably with the generalised opinions of the others at the committee table whose standing is often by tradition or habit (Little et al 2002). Holosko (2001) stated that disempowerment could occur at any level of the process where service user input and its impact disappears into a '*black hole*'.

Transparency has to be demonstrated and is an important consideration with regard to the role of service user input in decision making, whether it is seen as positive or negative in terms of the final outcome (Holosko 2001). This is also linked to benefits and barriers of involvement because to facilitate empowerment, public agencies must demonstrate to those who have been involved what difference their contribution has actually made. This would be the ultimate test of commitment to involving and facilitating the empowerment of patients and the public.

To conclude, perhaps patient empowerment depends on the perspective of who defines the problem: the doctors, the managers or the patients. If empowerment is meant to become a reality within Primary Care, however, both collaboration and partnership must be forged between Primary Care Organisations and the service users, whether directly or mediated through groups like the patient and public forums. Too often, in the NHS, initial enthusiasm for discovering views is shown, but ultimately there is little demonstrable change to service or policy. The consequence of this is a reinforcing of public suspicion and cynicism, as each time invited views are ignored the possibility of undertaking another involvement activity becomes more difficult. The importance of an organisational culture and ethos in patient and public involvement is considered vital in encouraging and empowering continued lay interest and involvement.

2.5 The Meaning of Community

Public or community involvement and participation have become reference points in health practice worldwide and have become the subject of considerable associated literature and commentary, in which debate about meaning is a common theme (Jewkes and Murcott 1996). The general idea of '*community*' has had a wide currency in social analysis and the ideas should have a close affinity. However, the literature devoted to community and public involvement has developed separately from discussions on community in social commentary. In the context of patient and public involvement forums, their initial purpose was to represent their local community on health issues. In discussing the broad notion of community with respondents, it became clear that there were different meanings and interpretations, which are discussed in Chapter 5.

To this end, people involved must interpret, define and operationalise the differing meanings. The Oxford Dictionary definition of community is a '*body of people living in the same locality*' and other authors like Suliman (1983), when discussing health being dependent on community participation, defined the same word as *'a group of people with a sense of belonging, with a common perception of collective needs and priorities and able to assume a collective responsibility for community decisions'* (p.407).

In health literature there appeared to be a general lack of consensus about how '*community*' should be defined. Several authors incorporated the notion of shared needs and Rifkin (1988) implied that community means *'specific groups with shared needs living in a defined geographical area'*. Many authors do link shared geographical location as an important element when defining community. However, Adams (1989) argued that the term could be defined geographically or as a community of interest, for example, a street, estate or women's group. This brief review of definitions revealed that there is a singular lack of agreement what the community is. Although there are recurring themes, many of the definitions are conflicting and suggested that what one person regards as community, another would not.

Jewkes and Murcott (1996) argued in their health promotion study that there was an importance difference between the meaning of community for '*members and non-members*' and that recognition of the differences in the construction of communities by both parties was essential. They add that the variety of meanings is potentially limitless, determined principally by when and in what circumstances '*community*' is constructed, as well as by and for whom. This gives rise to questions regarding the consequences of decision-making: whether and how such decisions differ as a result of the different meanings given to '*community*', and whether these influence what may be achieved by the participating community.

Gilroy (1987) argued that community is as much about difference as it is about similarity and identity. It is about boundaries, struggles, conflicts and is fundamentally a relational idea. Cohen (1985) also argued for two central ideas to be found in the notion of community: one aggregational, the other relational. The former related to the aggregation of people who have something in common which distinguished them significantly from members of other groups. The latter expressed the opposition of one community to others (Jewkes and Murcott 1996). His central thinking is that '*people become aware of their culture when they stand at its boundaries; when they encounter other cultures or when they become aware of other ways of doing things*' (p.69). In understanding, what the term understanding, what the term community meant to members it is necessary to understand the '*symbolic construction*' of the boundaries, which distinguish one community from another (Jewkes and Murcott 1996). This '*symbolic*' term referred to what the boundary meant to people or rather what meanings they give it (Cohen 1985, p.12).

Cohen (1985) argued that the boundary encapsulates the identity of the community and, like the identity of the individual, is called into action by the exigencies of social interaction. Boundaries are marked because communities interact in some way or other with entities from which they are, or wish to be, distinguished. The manner of this difference depends entirely on the specific community in question. Some, like national or administrative boundaries are enshrined in law. Some may be physical like a mountain or a sea and some may be racial or religious. However, not all boundaries are objectively apparent and may only exist in the minds of their beholders. This being so, the boundary concept may be perceived in rather different terms, not only by people on opposite sides of it, but also by people on the same side.

In rethinking the notion of community, we need to unpack some of its more hidden meanings, as well as its implications for social policy analysis. Firstly, the idea that community refers to a spatially bounded locality is problematic. This would tend to suggest that there is something natural, permanent and exclusive about such a place and that it is separate and distinct from other places (Cohen 1985). In the process therefore, internal divisions and conflicts are all too often neglected in the desire to project communities as harmonious. Communities will always be plural and overlapping, are formed, made and struggled over. Secondly, communities can be created from local and global links and globalisation can have significant consequences for people and localities.

They should not be seen as a once and for all entity: people can shift in and out of different communities at any one time.

The definitions of community invariably used in patient and public involvement programmes do not adequately address the aims of policy, which tend to talk of genuine involvement, reaching disadvantaged groups and addressing inequalities in health (Jewkes and Murcott 1996). Perhaps a more refined definition of community is needed that captures the relationships people develop between themselves to create communities. Any definition of community must include understanding of people's common sense of identity and the interactions they have with each other (Emmel and Conn 2004).

Bellos (1997) argued that the increasing diversity and complexity of modern life is reflected in new types of community. In rejecting the formula that communities of place are necessarily communities of common interest, we decouple the idea of community from a sense of place. Non-place forms of community and identity are formed and we can easily accept that there are multiple communities, that there is diversity, but the question of who belongs to which community remains.

Brown (1994) explored the meaning of '*community*' and '*participation*' in general practice. Brown noted the dominance of individualism in general practice perspectives and the lack of collective ethic in its organisation. However, since Brown's paper was published, primary care organisations have emerged, offering new perspectives on community, shaped by the core commitment to the health improvement of the local population. With the onset of the new GP contract, there has also been an associated shift to a more primary and community care based culture. The remit of the Primary Care PPI forums was much wider that other secondary care forums groups, particularly in consulting with primary care organisations and with powers of inspection and referral on to Overview and Scrutiny Committees, as appropriate.

Relationships between health and social care providers in the public, private and voluntary sectors and local communities are vital as collaboration is fundamental to any community strategy (Anderson et al 2002). This relationship needs to be fostered but voluntary and community sector organisations can assist in many ways: as collective voices of patient and public interests; as a source of intelligence around community needs; as partners in addressing these needs; as sources of expertise around the community and as a possible route for communication with more marginalised communities. However, any form of relationship is not a quick process or a simple linear step (Institute of Healthcare Management 2000), particularly in identifying common themes and addressing common interests.

Communities are dense and intense networks and the '*visible*' communities are localities that are empowered to seek social justice, such as the delivery of a particular service. However, there are also localities that do not have visibility and these excluded communities either lack power to have a voice, or purposefully ensure their networks are invisible from those in authority (MacDonald and Marsh 2002). These authors noted that many of these groups see health and social care providers as *'being in authority'* and are therefore reluctant to approach service providers. The people within these groups are often inward looking, seeking to isolate themselves because they feel threatened in some way. These invisible communities are often not represented and their voices are not heard in decision-making.

A term often used is '*hard to reach*' groups but what is really meant by this term? Data within studies or reports generally lists categories, for example, asylum seekers, travellers', black and ethnic minorities, homeless people, but why are these categories listed as being hard to reach? Is it that their behaviour deviates from the '*norm*', is it to do with cultural difference, impairment, or being over-targeted (being subjected to past targeting) or is it simply down to assumptions and the power of those assigning the term.

It could be argued that we can never realistically reach all these groups and individuals. There has to be a willingness to allow targeting or to allow representation and some of these categories may avoid getting '*involved*', or simply are not noticed by officialdom. Involvement with some areas of the community could be a big logistical challenge as well as a financial one (Coote 2006). Perhaps people are not concerned with their health unless a related situation directly affects them or someone close to them, or they just accept that what they receive is better than nothing.

So where does this discussion take us with the notion of community? Not perhaps with a clear sense of definition, but with an increased awareness of the contested, ambiguous and contradictory nature of community. Community is symbolic and perhaps exists as a necessary fiction, through which attempts are made to make sense of the world; whereby links are forged and through which mobilisation and resistance to marginalisation and exclusions can be conducted. However, alongside the awareness of diversity and differentiation, ideas of community continue to have a deep resonance (Hughes and Mooney 1998).

Finally, it is of interest to consider what we individually mean by '*community*'. Individuals often have small, often overlapping communities in their personal lives, for example, work community, school/university, social, friends and relatives but in the context of patient and public involvement, what is meant by the terminology? Perhaps for many of us the term '*community*' means the '*whole*' of our local population or geographical area. Papers like Jukes and Murcott (1998) discussed the meaning of community and acknowledged that it was almost impossible to get final agreement as it meant different things to everyone. Perhaps the deceptively simple notion of '*community*' is one of the most contested words in social science and health literatures.

In conclusion, community remains seductive as a means of promoting social justice and regulation, and along with the consumer and the citizen will continue to be socially constructed as a popular way of imagining social relations. This inescapably throws up issues of inclusions and exclusions, of responsibility and autonomy. The basic and fundamental point is that community in the 21st century has changed. We no longer know all our neighbours or socialise with our friends, we enjoy our leisure time in different ways and in different places. We construct new communities of interest, rather than place. Now people choose their associates – and perhaps more importantly, choose with whom not to associate. This does not mean that community has disappeared but that communities in today's world are different and continually meet different needs (Blunkett 2003).

2.6 Definitions, Ladders and Hierarchies

A definition of involvement or participation in the broadest terms is that it involves *'taking part in the process of formulation, passage and implementation of public policies through action by citizens which in turn are aimed at influencing decisions, which are, in most cases, ultimately taken by officials'* (Parry et al 1992, p.16).

Public involvement is, however, a mixed bag and there are many differing opinions about what should be in the bag, and what should be left out (Anderson et al 2002). For the purposes of this research study, to avoid conceptual confusion and due to the name of the forum groups, the terms '*patient*' or '*public*' have been used jointly around involvement in health care. Both participation and involvement arguably have transferable meanings and are both used to some extent within this study, however, the viewpoint taken in this research is that the term involvement implies association, connection and contribution. Some authors like Lenaghan (1999) have reflected on terminology around involvement, particularly around government papers, making the point that different government departments use the terminology of citizens, users and consumers interchangeably, with little awareness of the different strategies, which might be required for involving the public. An example is the government paper Patient and Public Involvement in the new NHS (Department of Health 1999) where service users and the public are frequently referred to in the same sentence and no differentiation is made between representation and involvement. Barnes and Wistow (1992) discussed and reflected on language, advising of its importance and the problem in finding a term acceptable to all.

The term '*user*' is commonly used around involvement, although not without controversy, because of its association with drugs and client is descriptive not of a person, but of a relationship (Simpkin 1979). It would seem that we tend to forget that whatever the terminology the term is not meant to be descriptive of the person, but of the relationship. Patients and the public, as in this research, can feel very strongly about being called a user, service user or customer, in relation to health matters. The identification of '*patient*' was much more prevalent and '*customer or consumer'* gave implications of shopping, which was seen as inappropriate. This literal sense of the term '*consumer*' was also identified by Keat et al (1992), as having associations with goods, services and commodities.

It was not that far back in NHS history when the patient was perceived as a passive recipient of the doctor/clinician (Shackley and Ryan 1994) and were conditioned that health matters were outside of their responsibility and involvement. At this time, the training of doctors did little to alter this viewpoint and doctors became the experts able to make decisions without too much recourse from the patient (Du Rose 2002). These attitudes had been built over many years although it is acknowledged that these attitudes are now changing. A number of papers, including the NHS Executive document on Patient and Public Involvement in the NHS (Department of Health 1999) and the Bristol Royal Infirmary Inquiry (2001) have highlighted the historical difficulties of involving patients and the public in decisions about their own health (detailed in Chapter 3, from page 102). The latter inquiry highlighted the attitudes of some health care professionals with regard to the parental relationship. It is the recognition of these challenges that has, in part, brought public involvement forward and to have more government priority, but it is still problematic for a passive public to become more assertive and challenge individually.

In the nineties, the public as a customer was a key theme, as was the growth of contractual matters, particularly in relation to GP fund holding (Le Grand et al 1991, Stewart and Stoker 1994). Attention was focussed on providers offering an exemplary service with speedier treatments if patients moved to other areas for treatment. At the time, there seemed to be indications of a postcode lottery and statistics were published to demonstrate the meeting of targets. These actions appeared to reinforce the concept of the public or patient as an individual with choice but the language and expectations of consumerism do not necessarily fit easily in the public domain.

Lowndes et al (1998a, 2001), Lowndes, and Wilson (2001) commented that members and government officers believed that the public would only get involved if their own interests were directly affected. The public participants attributed less importance to '*self interest*', but nevertheless participation was more likely to relate to the protection of their own or immediate community interests, rather than the '*wider*' issues. Some authors have commented on a natural progression for individuals and groups from that of individuals into public involvement. Barnes (1997) advised that as people develop more experience of involvement, they move from discussing the personal experiences of service to reflecting on how services might benefit people who use them. Lowndes et al (2001) commented that some members of the public find it difficult to maintain involvement and participation efforts and that there was often a tendency to rely on a few committed individuals. These '*natural joiners*' were often members of other community groups or were active in other forms of consultation. Millward (2005) discussed the opportunities for participation, which actually encouraged '*natural joiners*', because the nature of much modern participation required people like them. Focussing on natural joiners and their motivations rather than looking at why the non-joiners do not join, could increase the understanding of why people participate and could suggest ways forward.

Holosko (2001) discussed the importance of service providers valuing public view points otherwise those involved will feel pessimistic about their power to change organisational thinking (see Empowerment from page 52). However, building any relationship with the public would suggest that an organisation needs to be consistent rather than adopting a one-off approach, and some authors are critical of this lack of continuity (Bowling 1993). It is also important to remember that a geographical community covers a huge spectrum of health needs and any relationship has to reflect this spread.

The linkages between engaging patients and the public point to organisational strategies that do consult and address the stated priorities of the community, that actively recruit participants, that show results, keep the public informed and that employ a repertoire of methods to reach different groups (Lowndes 2001). An organisation has to be sincere about wanting to involve patients and the public for any such exercise to be successful Chambers (2000). Pickin et al (2001) discussed the factors and challenges to reorient statutory organisations so that they are better able to engage with communities. These factors fall into five domains: the community's capacity to engage; the skills and competencies of organisational staff; the dominant professional service culture; the overall organisational ethos and culture; and the dynamics of the local and national political systems.

Public involvement is certainly about the meeting of different voices and different interests. Ideally, it is about understanding differences, finding common ground and negotiating mutually acceptable solutions. It is also about valuing alternative perspectives and thinking about things in a new way. If this is what public involvement should be about, then the planning of public involvement should embrace similar values (Anderson 2002). In practice, patient and public involvement is always a negotiation between the individuals involved, and therefore changes as people come and go. This could mean that public involvement is defined too narrowly, and it is often forgotten that public involvement is about relationships, which can be sustained in many ways.

Staff involvement is also another frontier problem, as often staff members are treated separately due to professional interest (Anderson et al 2002). There is plenty of scope to overcome any perceived divide as they are also public voices in their own right, are patients, parents, carers or local residents. As a government priority area, there is ultimately a steady pressure on managers and clinicians to conform to policy. There are fears associated with actions needed to enable involvement and to satisfy the needs of the public, including their ultimate expectations. McIver (2000) discussed the problems of an approach where there was an implication that patient/public views would carry great weight, with health professionals fearing that expectations would be raised too high. The importance of effective communication is at the centre of 'involvement', particularly in a patient-professional relationship and can often relieve anxiety, despite the reality of waiting lists and lack of options. Maguire and Truscott (2006) identified a study perspective that explicitly '*joined up*' thinking across services, with the linked importance of service responsiveness.

Information and education can sometimes be considered not to count as involvement, because the relationship is one-sided, and the organisation learns nothing. This is highlighted in Arnstein's ladder of participation (1969). Nonetheless, it makes practical sense for information to be on public involvement agendas, as all involvement work must include some aspect of information, given to aid discussion. One therefore can argue that information and education are part of the process of enabling individuals and organisations to participate in health service decision-making.

The different stages or degrees from non-participation to citizen control were originally described by Sherry Arnstein in her 'ladder of participation', which described the power relationships between institutions and citizens. Arnstein's model consisted of a ladder (see fig 2.1 next page) with eight rungs representing different degrees of involvement. The first two rungs are seen as non-participatory, with '*manipulation*' being the persuasion of citizens to support existing plans and '*therapy*' the diversion of citizens from the real issues. The next set of rungs consists of modest degrees of involvement: informing citizens; consulting simply in terms of conforming with statutory legislation but without obligation to act or take notice of citizen's views; and placation, where there is a guarantee that citizen's views will be heard but no guarantee that they will be heeded. The higher rungs on the ladder identify forms of participatory activity in which the public has increasing power and where there is a commitment to ongoing integration of the views of the participants fully within the wider decision-making process. The higher rungs range from partnership (sharing decision-making) through delegated power (citizens have the dominance) to citizen control (full governance by citizens who have control of a project with a budget), with no intermediaries assisting them (Litva et al 2002).

Figure 2.1 – Ladder of Citizen Participation (Arnstein 1969, p.216)

	Degrees of citizen power
Citizen control	Local people handle the entire job of planning, policymaking and managing, with no intermediaries between them and the source of funds
Delegated power	Citizens hold a clear majority of seats on committees with delegated powers to make decisions. Public now has the power to assure accountability of the programme to them
Partnership	Power is redistributed through negotiation between citizens and power-holders. Planning and decision-making responsibilities are shared – e.g. through joint committees
	Degrees of tokenism
Placation	As an example, through co-option of local people on to committees. It allows citizens to advise or plan, but retains for power-holders the right to judge the legitimacy or feasibility of the advice
Consultation	Attitude surveys, neighbourhood meetings and public enquiries – but Arnstein believes this to be 'window dressing'
Informing	A first step to participation, but with the emphasis on a one-way flow of information. No channel for feedback
	Non participation
Therapy Manipulation	Non participative, aimed at 'educating' the participants. The job of participation is to achieve public support for the authority's plans

Brager and Specht (1979) (figure 2.2 next page) looked at a continuum of community participation in a similar way to Sherry Arnstein, but from the perspective of the organisation. The relevance to this research is that although these authors defined the highest level with control to the community participants, they stated there should be a willingness to help the community at each step to accomplish their goals. Again, this emphasised the importance of the organisational ethos.

Figure 2.2 – Brager and Specht's Continuum of Community Participation (1973, p.39)

Participants Action	Illustrative Mode
Has Control	Organisation asks community to identify the problem and make all key decisions on goals and means. Willing to help the community at each step to accomplish goals
Has Delegated Control	Organisation identifies and presents a problem to the community, defines the limits and asks community to make a series of decisions, which can be embodied in a plan, which it will accept
Plans Jointly	Organisation presents tentative plans subject to change and open to change from those affected. Expected to change, plan at least slightly and perhaps more subsequently
Advices	Organisation presents a plan and invites questions. Prepared to modify plan only if absolutely necessary
Is Consulted	Organisation tries to promote a plan. Seeks to develop support to facilitate acceptance or give sufficient sanction to plan so that administrative compliance can be expected
Receives Information	Organisation makes a plan and announces it. Community is convened for informational purposes. Compliance is expected
None	Community told nothing (bureaucratic paternalism)

Arnstein's ladder has provided the foundation for many approaches to participation and has been the benchmark for many papers, despite being published nearly forty years ago. Tritter and McCallum's (2006) critique notes that Arnstein's measure of participation is in the power to make decisions and that seizing control is the true aim of citizen engagement. However, they argue that this focus on power is somewhat insufficient for making sense of participation and involvement at a conceptual or practical level. Collins and Ison (2006) argue that it is perhaps time to jump off the ladder and suggest a shift in the thinking and practices of policy-making.

Tritter and McCallum identify three key factors that Arnstein's model does not consider. The first of these is the failure to differentiate between method, category of user and outcome. Many different involvement methods are required to secure participation in NHS decision-making at individual, group and organisational level and there are many factors, including trust, that contribute to these improvements. The theme of trust could be placed between placation and consultation in Arnstein's ladder, as there is a need for all parties involved to devote time and expertise in the process, to develop the capacity to participate effectively and to build some consensus around the forward plan.

Secondly, Tritter and McCallum identify that Arnstein's ladder has the potential to limit development and sustainability. The ultimate aim of citizen control may meet the needs of some people but takes no account of the depth of participation. An empowering system needs to take account of different view, protecting the rights of people and needs to make allowances for services to be tailored for differing needs. Innovative methods are required to actively engage those who might otherwise be ignored and have no voice.

Finally, Tritter and McCallum (2006) make the point that Arnstein's definition of user involvement is one-dimensional, based on the user's power to act in formal decision-making processes. This approach takes little account for the often overlapping, types of user involvement. User involvement may mean participation in treatment decisions or a feature of service delivery and roles may vary, but there are interactions and linkages between the different categories. The authors make the point that Arnstein's ladder only looks vertically – the relationship between the organisations and the individuals being served, and fails to consider horizontal accountability. They emphasise the importance of a model that accounts for different types of involvement that taps into communities of users, that draws people at different points in their life, and recognises that some people may not want to be involved.

It is interesting to reflect on Tritter and McCallum's (2006) paper and to observe that many of the earlier models give emphasis to the ultimate desirable end - being that of community or citizen control. In reality, the desired end is more complicated than just reaching the top of the ladder and is not necessarily the ideal for many members of the public. The extent to which the public should be involved in decision-making is therefore considered rather more complex than a straightforward devolution of power. It is also important to highlight the many other '*ladders*' or continuums have also been developed since Arnstein's model. Most appear as '*modifications*' of the basic model, but all of them reduce the number of steps from non participation to citizen control.

Feingold (1977) suggests five degrees of participation; informing, consultation, partnership, delegated power, and citizen control. Byrt (1994) advocated the provision of participative opportunities, even if these generate a poor response at first take up. His study of two voluntary organisations revealed that almost all informants would choose to be involved in some way, in decision-making and taking responsibility. He illustrated the complexity of the subject by putting forward an eight dimensional model of participation and concluded if consumer involvement is to be formalised it required careful planning.

McFadyen and Farrington (1997) looked at the five possible types of involvement put forward by Morris and Lindlow (1993). They argued that although these facets are important, involvement needed to be regarded more widely than simply involvement and consultation if it is to be effective. They listed a number of objectives for consideration such as: to allow opportunities for self-assessment, to offer opportunities for scope and control, where appropriate, to allow people operational control of the services they receive, and to acknowledge, respect and welcome campaigning organisations. They also stated that as well as the five types of involvement there are a number of layers of participation, which reflect the interface with either individuals or populations. They listed individual and population divisions, which define areas of relative responsibility, although there are many areas of joint responsibility.

The Institute of Healthcare Management's (2000) toolkit for public involvement in primary care (fig 2.3 below) highlighted a simplified seven-degree continuum of public involvement, simplified both in terminology and in the highest degree being partnership. Here organisations ask the public to identify the issues and problems and seek their own solutions but the organisations are willing to help the community at each step to meet their goals. Here the emphasis is on an equitable partnership between professionals and the public.

Figure 2.3 – Institute of Healthcare Management's Continuum of Public Involvement (2004, p.7)

▪ Partnership	Organisations asks the community to identify the issues and problems and seek their own solutions. Organisations are willing to help the community at each step to meet goals
▪ Participation	Organisations identify and present problems/issues to the community. It defines limits and asks the community to make a series of decisions which can form an acceptable plan
▪ Involvement	Organisations sit down with the community and plans service together
▪ Consultation	Organisations seek views of community and make a judgement about what to include in a plan
▪ Communication	Organisations try to promote plans and strategies and seek to gain public support for implementation
▪ Information	Organisations make plans and provide public with details about decisions made
▪ None	Community is told nothing

Charles and de Maio (1993) identified three categories of citizen involvement: consultation, partnership and lay control. They argued that involvement could take place in different '*decision making domains*' with policy issues, service design and resources on matters regarding individual treatments (Allsop et al 2004). At the partnership level members of the public are viewed as being more integrated into decision-making by formal mechanisms, for example, where public and professionals agree to share information and decisions, while consultation keeps the public outside the decision chamber, and lay control occurs where patients or the public, independently of professionals, ultimately make the decisions (Thompson et al 2002). This different approach by Charles and de Maio (1993) acknowledged that there are many considerations in patient and public involvement. It seemed much clearer in distinguishing some boundaries that could be understood by all parties, a common cause of concern in developing working relationships. Theoretically, and as an example using this model, there could be consultation with the public on policy matters, lay control on service design and resources, and partnership with patients around their own treatments.

In conclusion, it is all too easy for organisations to talk about partnerships, when they do not intend to share any decision-making. The word '*partnership*' can be seen as being a vague word but a continuum can encourage people to explore what is meant by it and to be clear before matters end in disappointment. It is still far better to have a good consultation process than to offer partnership and then fail to deliver on it (Anderson 2002). Any form of involvement or participation is therefore a complex concept in theoretical terms and its complexity is clear when applied to a health care situation. Continuums can be useful tools in thinking about the balance of power between the organisation and the public but discussion is needed from the outset so all parties are clear of the boundaries.

In agreeing with the thinking of authors such as Lowndes and Wilson (2001) and Tritter and McCullum (2006), there are varieties of involvement methods that are necessary to tap into communities of users, drawing people at different stages of their lives, illnesses or care, to ensure relevance for different types of user involvement. Tritter and McCullum advocate a mosaic tile approach due to the complexity and interactions between users, their communities, voluntary organisations and the healthcare system, on which successful user involvement depends. The mosaic runs both vertically and horizontally, illustrating the necessity of the relationships and the connections with individuals at local, organisational, regional and national levels.

Other authors have highlighted the difficulties of attempting to have a representative sample of individual, representative from particular populations from the outset (Lowndes et al 2001), and could feasibly block attempts to start a process. Although this may be an ultimate aim, the challenge is to allow and provide the opportunities for involvement, which were not always obvious in the PPI forum system, given the exclusions and recruitment procedures. Invitations to all local people and groups interested in health could bring a wide-ranging perspective of views and a depth of ownership in policy and practice at both individual and community levels. Further roles can then be developed, although all those willing to participate can be linked into their own treatments and care and can give their views on the wider aspects of service design. Agreeing again with Tritter and McCullum (2006), meaningful user involvement can only be achieved if evaluated, to explore viewpoints on the process and measure the effects of decisions about treatment and service development. Without evidence that involvement makes a difference and change happens as a result, there is little hope that individuals or groups will remain engaged and equally health professionals will remain somewhat sceptical of the value of that engagement.

2.7 Benefits and Barriers

The argument that public services should become more responsive and accountable to public needs has in effect been won – in theory at least. While it is generally acknowledged that it is not that easy to achieve in practice, there is some evidence, although not all clearly substantiated, that indicate a number of benefits. Proponents of patient and public involvement have identified some benefits to individuals, organisations and communities (Coulter et al 2006, Ridley and Jones 2002, NHS Executive 1998). These benefits included:

- better treatment outcomes, services more appropriate, responsive and effective
- increase accountability leading to increase confidence in health services
- improvements in staff and patient morale
- improvements in safety and reduction in complaints
- empowerment of individuals and communities
- improved health and a reduction in equalities

However, Coulter et al (2006) explained that patient and public benefits are different and current NHS Organisations only attempt to consult with the public on planning and service development, with little being done to tackle the quality of the interactions between individual patients and the clinician, who form the front line of the service. The author concluded that to engage and empower patients directly there has to be a change in the culture of clinical practice, the face-to-face contact being the most important point for patients with only a small minority wanting to sit on committees or to be consulted on service developments that do not actually affect them.

There are examples within the literature of positive claims for user and public involvement in health services. Wilson (1999) highlighted the validity of involving people in health services indicating that people are the best judges of the service's strengths and weaknesses. The Department of Health (1999) claimed that involving people in decisions that affect them had a positive impact on self-confidence and self-esteem. In Strengthening Accountability (Department of Health 2003), the guidance states that: '*Patients are the most important people in the health service. Too many people feel talked at, rather than listened to, this has to change'* (p.vii). Weale (2006) highlighted a number of reasons for involvement: the first and most obvious is that the public are users or potential users of health services and need to be asked about the quality of care. Secondly, patients, particularly with long-term conditions, have considerable and valuable technical knowledge, built from direct experience. Thirdly, to rectify any imbalance in policy by securing balanced representation of user and provider views.

Notwithstanding these benefits, there are obstacles, challenges and barriers that stand in the way of developing effective patient and public involvement. The NHS Executive (1998) stated that health care professionals could feel threatened by the notion of involvement due to their professional training and background. Where there is poor understanding of patient and public involvement meaning, involvement activities can be uncoordinated and involvement seen as an add-on to existing work. There is lack of clarity and lack of ownership across organisations, which in turn leads to limitations as to what is achievable.

It is vital for organisations to be clear on these purposes from the outset. Patient and public involvement clearly needed to be integral to the ethos of the organisation, built into the culture and responsive to both the public's needs and to those of the organisation.

Walt (1998) looked at how much people within organisations can be involved in building the strategic implementation process for considering any health care reform. She advocated using involvement as a powerful mechanism that will support readiness for change but it prepares those involved for the changes required of them (table 2.4 below), for example, in establishing milestones by which a change programme will be executed, looking at variances from budgets, and resources allocated and monitoring results. Using this type of instrument can avoid pitfalls in the implementation of change, and organisations need to consider and plan for working with communities.

Table 2.4 Instruments in policy analysis, which can be used, for planning and managing the implementation of change (adapted from Walt 1998, page 379)

AREA OF ANALYSIS	PLANNING ACTION
Macro-analysis of the ease with which policy change can be implemented	Analyse conditions for facilitating change and, where possible, make adjustments
Making values underlying policy explicit	Identify macro and micro level values underlying policy decisions. If values conflict with policy, support will have to be mobilised; costs minimised
Undertake stakeholder analysis	Review interest groups likely to resist or promote change in policy at national and institutional levels; plan how to mobilise support by consensus building or rallying coalition of support
Analysis of financial, technical and managerial resources available	Consider costs and benefits of external funds; review salary levels, incentives to change behaviour, review need for training, need for new information systems or other resources; inducements and sanctions
Build strategic implementation process	Involve planners and managers in research, and analysis of how to execute policy; identify networks of supporters of policy change; clinical champions, manage uncertainty; promote public awareness campaigns; institute mechanisms for consultation, monitoring and 'fine tuning'

Strategies for involvement are clearly difficult and complex and many involvement strategies initiated in primary care are often seen as no more than 'tick-box' exercises intended to fulfil policy demands, rather than truly address the needs of communities (Milewa et al 1998, 2002). Policy makers often feel threatened by communities, and barriers can be erected to ensure that people do not play an active role in decision-making about services developed for them. Other studies with communities (Hollins 2001) do indicate however, that people have a sophisticated understanding of their own condition and how their individual health needs can be improved. True involvement therefore requires a change in the relationship between professional and the public although recognising that any strategy will bring into question presuppositions among professionals on service delivery (Emmel 2004). This raises questions about power, who controls, who directs and who decides on what is most appropriate.

Difficulties with the concept of representative participation are often at the core of concerns about involving people (Hopton and Hill 2001). Concerns about how to avoid tokenism, finding representatives who are able to focus on broad rather than single issues, involving '*hard to reach*' groups and, avoiding domination by specific interest groups are frequently at the heart of the hesitation to involve people. Finally, the obstacle of cost in terms of time and money has to be acknowledged as a very real problem (Cole 2001). Money and payment for involvement in the patient forums was a contentious issue and one that warrants further discussion as it is raised in other literatures. The Statutory Instrument Regulation (2003) on membership and procedure, stated that patient's forums were allowed to reclaim travelling or other expenses (including compensation for loss of remunerative time).

Other literatures look at the principles and practice of reimbursements in health and social care. Indeed, the government set out its own guidance for paying and reimbursing service users and volunteers (Department of Health 2006). In this report the statement is made that people need to feel supported, and for their contribution to be valued. There are obviously many ways to do this; being thanked, receiving acknowledgments or seeing improvements but payment is also an option, not least in the payment of expenses incurred. The report aimed to identify the areas that should be paid and attempted to link increased commitment, time, skills and expertise with the increased need for payment. However, the major issue is that paid involvement comes within employment law and can often mean that most people on benefits would face a financial reduction in real terms. By definition and certainly from the profile of this research, the people who are able to be involved could be people with time, like the elderly generation, or people with disabilities or they could be carers. It is also likely that a fair proportion of these people would have low incomes and could be in receipt of income related benefits and for these people remuneration or reimbursement is not straightforward.

A Stronger Local Voice (2006) stated that the government recognises the crucial contribution that patients and carers can make, often expertly placed over some years to contribute to all aspects of service planning and delivery. However, the people whose quality of life depends on health and social care services are often in receipt of incapacity or means tested benefits and these systems actually function to prevent user participation, which seems completely at odds with the government climate of encouraging patient and public involvement. The potential loss of benefit could be problematic and the potential associated processes of review and investigation, could have detrimental affects. There is also confusion about whether expenses can or cannot be paid, without affecting benefits. In the past, it was somewhat simpler to make token payments but the 1999 National

Minimum Wage Act increased protection for employees and for the first time, there was inclusive legislation that both employers and employees could not opt out of.

A social care report (Turner and Beresford 2005) looked at the national launch of the national user network 'Shaping Our Lives'. The report showed that social and health care services valued and wanted to make use of public input. The report also showed, however, that the benefits systems were at times inflexible and were inconsistent in the way they operated.

Of course, not everyone involved requires or agrees with payment and therefore it is important to give individuals the choice about payments. Others, whilst not necessarily opposing payments, can have concerns that remuneration could give service providers an element of control over the involvement process. Ultimately, the giving or withdrawing of money could give the provider control in terms of what they want. Alternatively, if a service provider has paid for training or other benefits then they may have a right to expect something in return, particularly in terms of reliability and behaviour. These concerns reflect further towards the issues of independence, which were raised in this study and are discussed further within Chapter 5 and 6.

Are people therefore put off becoming involved because of the potential problems created, or indeed would the offer of payments be an incentive to encourage wider participation. There is a stark divide between working for a living and receiving benefits, so there must be a possibility of having a system that blurs these distinctions and applies incentives to reward community work and active citizenship, whilst maintaining the benefits safety net (Turner and Beresford 2005). At the same time recognising that, some people's reasons for involvement are more about confidence and self worth and the wish to help others less fortunate.

2.8 Conclusions

This chapter has discussed some of the many theories and policy streams that have shaped patient and public involvement practice, and which are relevant to understanding the role of PPI forum groups. The review of literature has highlighted a framework and variety of questions about the ways in which a set of formalised structures for lay involvement in health services planning and scrutiny might represent a strengthening of the democratic basis of public policy and practice.

The two broad approaches associated with involvement, namely consumerist and democratic, have been identified. The latter forms the main emphasis in this research. The democratic approach was primarily discussed within this thesis because the traditional NHS system and equity principles have required that there be equal access to treatment for equal needs and these fundamental principles were important factors to the PPI forum members. The democratic approach relates to people in their capacity as ordinary citizens and taxpayers with rights to access, services and to contribute or participate with others collectively in the society in which they live. Democracy is defined not just as an association of individuals determined to protect themselves, but is taken to be a realm of active freedom in which citizens come together to shape the world around them. Within the context of the NHS, the decision-makers are accountable to the governed, this being accountability in the strong sense (Klein and New 1998), which should demand sanctions if the decision makers fail to satisfy. This is located primarily in the accountability of government to the people through Parliament. There are also debates about the extent to which the NHS can or should be tied more closely to local political structures and the hard accountabilities they mediate. Enhancing local accountability is part of a wider debate of whether the NHS should be more independent from government and is an ongoing objective of review within the NHS (Department of Health 2007).

To date, local accountability has been essentially in a '*soft*' sense, which is the requirement to justify decisions and performance with the governed. Debates about public values capture the sense of responsible decision-making that recognises forms of scrutiny and responsibility against and through which, decision maker's answer for their actions (Moore 1995). Whilst decision makers might emphasise the balance of evidence as a basis for decisions, democratic theory presses for procedural tests of the quality of the decision. In democratic theory, decision-making is valid if it is based on an appreciation of the range of interests, on informed deliberation among interests and on an aggregation of preference: it is governed, generally, by an intricate body of rules and convention (Newman 2001). These now extend beyond the traditional institutions of representative democracy, which is viewed by some authors as insufficient in complex societies. In developing a wider set of accountabilities, ideas of corporate governance, (for example the Langlands Commission) have sought to independently codify 'standards' of conduct for public services and these have been extended in more inclusive ideas of community and local governance (Newman 2001).

Such ideas specify arrangements for involvement that promote transparency and a free flow of information. In terms of involvement, processes, decision-making should be permeable, allowing opportunities for the governed to express their views and to influence the outcome. From the perspective of democratic governance, the process of deliberation and dialogue are continuing, and any mandate has to have constant review with testing for acceptability along the way. Finally, and related, the actions of decision makers must recognise rules of conduct designed to ensure equity in the treatment of citizens.

The democracy debates that were reviewed, all discuss the importance of power in the process of participation and how normatively, equality, diversity and difference should be accommodated. Those seeking to enhance participative democracy raise questions of '*how much*' power should be distributed: this is captured more clearly in the *'ladders'* and '*continuums*' of participation, discussed within this chapter. Whilst there are clear rationales for and benefits anticipated from effective patient and public involvement, there are also several obstacles, challenges and barriers. In terms of democratic rights, involvement in decision-making is still under developed (Hogg and Williamson 2001) and the work of most other health consumer groups has been limited in their efforts to expose the shortcomings of health services (Baggott et al 2005). Moving towards more democratic forms of health care have implied a shift from the more traditional professional model towards one of involvement, participation and partnership. It would be interesting to judge where the PPI forums have reached using a continuum like Arnstein (1969), although it is noted that any particular practice should be set in the context of other opportunities for engagement. This follows arguments by authors like Tritter and McCullum (2006), which emphasise and value the inherent complexity of patient and public involvement, and suggest the relevance of different types of involvement, and a system that could integrate both one-off and continuous involvement, negotiated by both users and professionals.

Democratic theory has linkages to debates about community, as a form of collective organisation and identity and one that has political significance. The meaning of community has become the subject of considerable associated literature and commentary, in which debate about its meaning is a common theme, particularly when imported into the discourse of social science. Over the years, it has proved to be highly resistant to satisfactory definition, perhaps for the simple reason that all definitions contain or imply contentious theories. All individuals generally have inter-related '*communities*' within their lives but these can be personal, professional or even geographical and have complete variety and variation in terms of numbers. Any community development demands involvement between communities and service providers that work right across systems and sectors and considers a range of linked issues. Governments and service providers have acknowledged that input is essential to help them deliver services that meet people's needs and to improve standards. Fundamental to this input is encouraging and empowering people to become involved and the first important question identifies who volunteered, the reasons for forum member involvement with detail on the composition of the lay PPI forums. It also questions member recruitment processes and training to give understanding and conclusions as to whether this reform added to the quality of knowledge and learning around the subject area.

Any form of involvement or participation involves a whole range of activities and methods and many political theorists have looked and identified a number of accounts of what motivates, or might motivate, participation and involvement (Parry et al 1992, Barber 1984, Pateman 1970). This chapter identified some primary political models or theories of participation, which are transferable in the context of health. The case made by participatory theorists is that if ordinary citizens engage actively in politics, the quality of democracy will improve. These writers believed that the task of governing was not just for elites, and in turn, this led to greater interest in how individuals might become engaged in political debate and decision-making. This raises the question of whether involvement is fundamentally about political legitimacy or is it, actually about continual improvements for all citizens.

Of course, not all people want to or can give opinions or voice concerns about the quality or indeed the lack of health service they receive. Linked, therefore, to health service improvement are the issues of representativeness and representation. There is little doubt that the notions of representativeness and representing others are very difficult concepts. An individual may be representative in terms of ethnicity, but do they truly represent the opinions and concerns of their local population as a whole? Is it also important to have representativeness or ethnic balance within any group claiming to represent others?
In terms of the PPI forum groups, there were Regulations (CPPIH 2003) and rules indicating that the forum groups should fully represent their local communities and the next question identified is whether the PPI forums were able to achieve this, given the importance of what PPI forums were expected to do. What were the volunteers understanding of representation and their relationships with their '*communities*'? Conceptually, a more realistic model of patient and public involvement (Tritter and McCullum 2006), may require a move from the dichotomy of representative versus other, to a method of involvement that could tap into people at different stages of their life, illness or care.

It is also argued that involvement and empowerment are complex phenomena through which individuals formulate meanings and actions that reflect their desired degree of participation in individual and societal decision-making (Tritter and McCullam 2006, Lowndes and Wilson 2001). Conceptually, patient and public involvement is more likely to fail, when there is a mismatch of expectation or indeed method. Therefore, involvement requires robust and open structures and processes that are legitimised by both participant and non-participants, and are both empowering and enabling, involving the NHS organisations plus the community and individual. However, the user must have license to be involved in shaping the methods used for involvement, and these may well be subject to change. This type of approach is more likely to lead to more efficient and effective involvement from the perspectives of both the patients/public and the health professional. Another question identified is the importance of the voluntary member expectations and understanding of the processes in place to encourage and develop the PPI forums, their activities, and work programmes.

Historically, there has been confusion about the nature of patient and public involvement and there is a real necessity for it to be integral to the ethos of an NHS organisation, built into the culture and responsive to both the public's needs and to those of the organisation itself. Often an organisation needs to challenge its own ways of working, as engagement with the wider public requires an effort to understand the local community and then to build a relationship of trust. Their will be tensions and challenges particularly when services are set against traditional ways of providing services (Department of Health 2004). This local relationship and the communication with patients and the public, albeit individually or within groups, is vital for any organisation to be successful. Therefore, the next question must identify the relationships between the PPI forums and their respective and associated organisations. What are the relationships between the PPI forums and these organisations, as a means of making comparisons, particularly if this had some bearing on overall PPI forum success? Perhaps surprisingly few organisations are pro-active in getting to the basics of knowing how communities themselves engage or their ways of communicating. It is important to note that involving the public is hard work; it takes a long time, can be traumatic and seldom leaves an initial feeling of euphoria. Conceptually, involvement is seen here as a process of taking small steps, incrementally establishing a system of engagement and relationships, and finally creating the conditions in which institutional trust, which may have been destroyed by years of unfulfilled promises, can be restored.

Developments over the last decade have responded to the growing pressure to be proactive with community viewpoints and the subject has been well documented, as detailed in Chapter 1, in an abundance of papers (Department of Health 1999, 2001a, 2001b, 2002, 2003, 2006), with mandates for more direct forms of patient and public involvement. These papers set out the requirements of engagement with users in the health service and set out the organisational changes need to deliver it. The importance, therefore, of identifying and building sustainable local working relationships cannot be over-estimated, and more recent government directives (Department of Health 2007) have strengthened the necessity for NHS Organisations to make patient and public involvement a priority. Patient and public involvement is certainly about the meeting of different voices and different interests, and the subject is very complex. As a concept, it must be about understanding differences, finding common ground, and finding ongoing solutions. It is also about valuing alternative perspectives and thinking about things in a new way and in practice, it will always be a negotiation between the individuals, communities and the organisations involved. The final question raises debate about the future of patient and public involvement in health, given the intended new reform of LINks, and the disbandment of

PPI forums. What lessons for the new organisations can be drawn from the experiences of the PPI forums, in moving the patient and public involvement agenda in health forward?

The next chapter will look at the historical context of patient and public involvement from the Community Health Council era in 1974, indicating the key government policy drivers, and the relevant literature in this area. The chapter also describes the system of patient and public involvement forums, and the associated and linking organisations.

CHAPTER 3

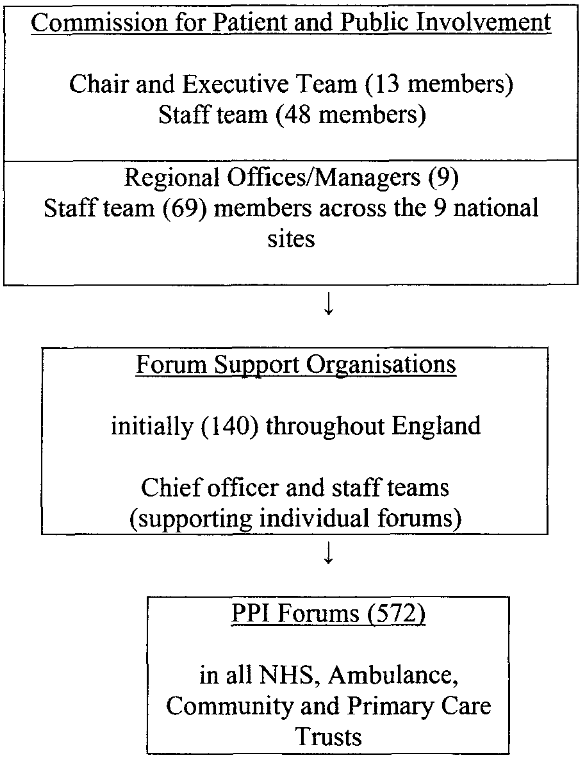
PATIENT AND PUBLIC INVOLVEMENT IN THE NHS

3.1 Introduction

This chapter describes both the historical and recent context of NHS patient and public involvement since 1974, when Community Health Councils (CHC's) were hastily established by the government as statutory, independent organisations for public opinion. CHC's continued for virtually thirty years, until December 2003, when Patient and Public Involvement Forums replaced them, initially with the intention of democratically representing and speaking for patients and users of the Health Service rather than auditing the performance of the service and handling complaints, the more traditional governance and ultimate guardian role adopted by many former Community Health Councils.

NHS primary care patient and public involvement forums, the central theme of this research, are described in some detail within this chapter (from page 110). Their national statutory organisation, the Commission for Patient and Public Involvement in Health, and the Forum Support Organisations, the independent not for profit organisations contracted to support the individual PPI forum groups are detailed separately (from page 120). There are also separate sections on the linked and associated services of the Patient Advocacy and Liaison Service, the Independent Complaints Advisory Service and Overview and Scrutiny Committees. PPI forums were linked to all NHS Primary Care, Hospital, Community and Ambulance Trusts. In combining the joint numbers of Trusts, there were an original total of 572 PPI forum groups in England. The structure of the formal PPI forum system is detailed, diagrammatically, on the next page (diagram 3.1).

Diagram 3.1 Structure of Commission of Patient and Public Involvement in Health, Forum Support Organisations and PPI Forums


Commission for Patient and Public Involvement

Chair and Executive Team (13 members)
Staff team (48 members)

Regional Offices/Managers (9)
Staff team (69) members across the 9 national sites

↓

Forum Support Organisations

initially (140) throughout England

Chief officer and staff teams
(supporting individual forums)

↓

PPI Forums (572)

in all NHS, Ambulance, Community and Primary Care Trusts

Through nine regional centres, the Commission for Patient and Public Involvement in Health managed Forum Support Organisations (FSOs). There were initially 140 Forum Support Organisations, although this number was to fall to approximately 70 by the third year due to a range of difficulties. The more effective forum support organisations took over more PPI forum groups during the three-year period 2003-2006. The FSO's were appointed following a national tendering exercise run by the Commission itself.

Foundation Trusts are reviewed separately, (from page 130) as the government agreed that they would have to retain patient and public involvement forums and it was intended that the Primary Care forums should add this aspect as they developed. The basis of foundation status is described, as there are implications for future patient and public involvement.

3.2 Historical Context of NHS Patient and Public Involvement from 1974

Community Health Councils (CHCs) were created following a reorganisation of the health service in 1972 and were commonly known as the *'public watchdogs'* for the NHS. In a national study of CHC's during 1974, Klein and Lewis (1976) reported that each Community Health Council had 30 or fewer members, seven out of ten were over 45 years old and the membership was equally proportioned between men and women. The voluntary and co-opted membership was unpaid but each CHC operated with a paid chief officer and support staff. CHC's were intended to provide a vital link between health care organisations and the users of health services. Klein and Lewis (1976) commented that there had actually been little thought about how these statutory bodies, charged with assisting, advising and consulting patients/consumers would, in practice, assist the *'interests of the public'* within the NHS.

In practice, although the work of the CHC's was defined on paper, the actual role centred upon pursuing individual complaints and speaking on behalf of communities in formal consultations around proposals for change in health services which meant, not surprisingly, that the result was considerable diversity between CHC's. The extent to which, and the ways in which they performed these activities varied considerably. Martin (1990) commented that CHC's were left to their own devices without mechanisms for evaluating how they carried out their functions or requirements to provide this specific range of services. The introduction of the CHC had provided an initial element of local democracy to the NHS and acted as a channel for consumer views to the local Health Authorities and practitioner committees in existence at the time (Buckland 1993).

There were over 200 Community Health Council's in England and Wales, and each CHC had between 16-30 members of the local community. Half of the members were appointed by the local council, one third were elected by local voluntary organisations and the remainder appointed by the Department of Health. In addition, the CHC could co-opt people with specialist skills or with a particular interest. Their proposed legal duty was to represent the interests of the community in the NHS and they had a legal right to be consulted and to have formal meetings with the Health Authority, to enter and inspect NHS premises and to receive information.

Community Health Councils may have started out in the general direction of democracy and participation (ACHCEW 1995) but their development suggests that they turned into a more practical commitment for action. There was certainly clear ambiguity in the comparison of phrases used to define the role of the CHC's. The 1971 White Paper (Department of Health and Social Security) attempted to describe them as '*bodies to represent the views of the consumer'*. However, at the second reading (House of Lords 1972) the phrasing was *'their basic function will be to represent the interests of the public in each health district'* (p.15). Any difference in wording may seem pedantic but the practical implications of the two definitions are more considerable. The interests of the consumer may not be identical to the interests of the local community as a whole and representing the interests of the public is considered different to actually representing the public. There were problems about the composition of CHC memberships and around the specific meaning that was given to the mandate to represent the community; in particular, the difference between being representative and representing (discussed more fully in Chapter 2, from page 37), was an important axis in debates about the value of CHC's (Martin 1990).

Although there were some positive signs and increasing emphasis on consumer rights during the late 80's and early 90's with government documents like Working for Patients (Department of Health 1989) and The Patients Charter (Department of Health 1991), the statutory rights of the Community Health Councils was not increased. Winkler (1987) stressed that consumers should not be a part of Health Authority management but instead should have a partnership with management if they are to be effective in representing viewpoints in the NHS. Therefore, CHC's have had to walk a fine line between being too confrontational or working too close so they could stand outside and criticise objectively. In being effective in their role, CHC's needed to consult with the public. This raised issue about the representativeness of CHC's: whom should CHC's be consulting with; how should CHC's consult; and how representative were CHC members themselves of members views? There were also issues as to what areas CHC's should have been consulting on: services, medical issues or strategic issues.

From initial concerns that public services were not achieving their aims (Klein and Lewis 1976), government interest became linked to doubts about the efficiency and quality of public services. Public participation was encouraged in government documents as a way of tailoring services more closely to user's needs. The 1983 Management Inquiry led by Sir Roy Griffiths was one of the influences that lay behind the concern to make services more responsive to users. One of the recommendations of the Griffiths Report was that health service managers should carry out market research to find out the needs of service users, with the idea of being responsive, to tailor the service appropriately and to provide an efficient service. The theme here was ultimately providing a service, which could be cost-efficient, but one that remained responsive to shifting public concerns and debate.

Towards the end of 1987, the Thatcher Government reviewed the health service and the reforms led to the NHS and Community Care Act (1990), which introduced an internal market, separating the responsibility for purchasing services from that of providing services. The purchaser function was the responsibility of health authorities and in turn general practice fund holders, whilst the actual provision of services was made the responsibility of NHS Trusts. The internal market was used as the primary mechanism for the allocation of resources throughout the 1990's (Macpherson 1998).

Of all the reforms at this time general practice (GP) fund holding received the most attention, both in terms of debate and research (Le Grand et al 1998). However, it is interesting to note that evaluation of the scheme as a whole appears to be limited and most research studies focussed on fund holders experiences and assessments in terms of process (Audit Commission 1996). General Practitioner fund holding, which followed the 1989 paper, Working for Patients (Department of Health), did little to enhance direct public representativeness or choice on the part of the patient but the terminology did signal an awareness that patients might be or want to be more than passive recipients of healthcare.

By giving general practitioner (GP) practices the option of holding their own budgets to purchase a range of services, the Conservative government extended the principle of separating the purchase and provision of services and clearly had specific objectives. These included reducing inefficiencies in provider organisations, creating improved quality in secondary care, enhancing GP practice facilities for patient care and promoting greater choice and responsiveness to local health need. The GP was the gatekeeper to other health services and was arguably in the best position to choose, arrange and respond to the health care needs specific to the individual patient (Le Grand et al 1998).

The importance of involving users in order to make health services more sensitive to their needs was increasingly emphasised in government guidance, but particularly in association with the 1991 re-organisation of the NHS. The Community Care Act (1990) and the Patient's Charter, launched in 1991, made patients rights explicit for the first time. In parallel, the NHS Executive produced guidance, which encouraged greater consultation with users and the public. Most of this guidance like Patient Partnership: Building a Collaborative Strategy (1996) and Priorities and Planning Guidelines for the NHS (1997/98) concerned patients and users rather than the public as a whole.

A key document, introducing the wider public's interest in health services policy and decision-making was Local Voices (Department of Health (1992): The document made it clear that the Government expected Health Authorities to take into account the needs and preferences of local people when purchasing services. This paper responded to the growing pressure to be proactive in seeking community views. It introduced the notion of Health Authorities as '*champions of the people*', and that their decisions should reflect, so far as practical, what people wanted their preferences, concerns and values. Although Local Voices encouraged the involvement of people beyond that of the direct service user, it did not use the term citizen or refer to the accountability to the public (Barnes 1997). The need to enhance public involvement in the NHS also had to be seen in the context of a wider debate about the nature of democracy in our society (discussed within Chapter 2). Nevertheless, it could be said that the document encouraged a closer relationship with the then Health Authorities and the public, and advocated greater public influence over purchasing decisions. Barnes commented that in practice, Health Authorities interpreted Local Voices in very different ways and there were wide variations in the methods used and the extent to which the public was involved. McIver (1995), Bowie et al (1995) and

Lenaghan et al (1996) all noted that attempts have been made to engage the public in priority setting, using approaches such as surveys, workshops, health panels, discussion groups and citizen juries.

During 1996, the Labour Party, whilst in opposition committed itself to enhancing quality and developing structures '*to enable patient's views to be heard*' (Labour Party 1996). Accordingly, this commitment featured prominently as one of the main reforms to the NHS after Labour was elected to office in 1997. The NHS was operating within a centralist NHS bureaucracy, reflecting a general view that patient-centred services required direct local democracy and demand-led care. Ultimately, the 'commissioning' role of Health Authorities and GP fund holders passed to local Primary Care Groups (PCG's), which ultimately have been restructured as Primary Care Trusts (PCT's). The Primary Care Groups and Trusts were instructed to involve the patients and public in the planning and commissioning of services. In the government paper Patient and Public Involvement in the new NHS (Department of Health 1999), the government advised that patient and public involvement needed to be integral to the way in which PCG's worked.

The structure of the United Kingdom health system has therefore undergone major change, since the White Paper, The New NHS: modern and dependable (Department of Health 1997) set out the original plans and The Health Act (Department of Health 1999) led the legislative changes. The New NHS white paper put forward a '*third way*' of running the health service – based on partnership and driven by performance. The paper set out the approach, which promised to build on the efforts of NHS staff to overcome obstacles with the internal market, building on the moves, which had already taken place in the NHS to move away from outright competition to a more collaborative approach. The White Paper described the approach as 'a new model for a new century', and was based on six principles (www.nhs.uk 2002):

- to renew the NHS as a genuinely national service, offering fair access to consistently high quality, prompt and accessible services right across the country
- to make the delivery of healthcare against these standards a matter of local responsibility, with local doctors and nurses in the driving seat in shaping services
- to get the NHS to work in partnership, breaking down organisational barriers and forging stronger links with local authorities
- to drive efficiency through a more rigorous approach to performance, cutting bureaucracy to maximise of budgets spent on the care of patients
- to shift the focus onto quality of care so that excellence would be guaranteed to patients, with quality the driving force for decision-making at every level of the service
- to rebuild public confidence in the NHS as a public service, accountable to patients, open to the public and shaped by their views

The last of the six principles indicated that the NHS would be shaped by the views of the public but left the context and the questions of how, when and where completely unanswered.

So why was there an ultimate government interest in NHS patient and public involvement? The NHS Plan for England (2000) was a government response paper to media criticism about the governments handling of the NHS and promised a new system of patient and public involvement. The Labour Government also introduced, or certainly intensified changes and modernisation to the role of the state and the nature of power and authority in society (Newman 2001). Labour placed great emphasis on public and user participation in public services and stressed the importance of citizenship. These changes focussed on the modernisation of central and local government and moved towards a more inclusive policy process. Part of these changes meant the modernisation of public services, including the health service. Part of this modernisation agenda meant securing the co-operation and regulation of health professionals and managers in improving performance and managing change. The Labour government's programme of modernisation also developed a more significant role for the voluntary and community-based sector, and placed a stronger emphasis on collaboration and partnership. The development of standards was linked to the increasing emphasis on quality in public services, which actually developed during the latter part of the previous (Conservative) government years.

"The choice is not a new NHS or the current NHS. It is the new NHS or no NHS (Dobson 1999, page 18). The emphasis on national standards with local flexibility appeared to reflect a shift in the role of the state towards influence and enabling rather than the exercise of direct control. However, the actual outcome seemed one of confusion by patients and the public, with professionals feeling embattled (Davies 2000, page 288), and the programme of modernising public services invoked a more centrally-driven and strongly managerial form of governance which appears in contrast to the more network-based governance proposed.

The argument for greater involvement in health services decision making ran alongside reforms within the NHS itself. The case for greater public involvement was made substantially in terms of its instrumental value – that is, improving decisions themselves.

However, the reforms also made it clear of the requirements to find new ways of engaging the public in decision-making, and called for '*democratic renewal*' to address the weak accountabilities identified as a feature of the welfare state (Baggott 2005). One of the significant developments under Labour was the introduction of a system of clinical governance in health (Newman 2001, Department of Health 1998a).

Clinical governance is viewed here as a strategy to strengthen systems of professional self-regulation, but accompanied by managerial mechanisms of quality control, and the Commission for Health Improvement was charged with responsibility and power to tackle shortcomings. All of these strategies were reinforced by audit and the development of audit and inspection was liked to a wider discourse of failure, and the possibility of threats and sanctions against organisations performing poorly (Newman 2001).

The whole issue of public involvement and the NHS in terms of accountability to patients is an interesting discussion. In the government publication, Delivering the NHS Plan (Department of Health 2002) a chapter was dedicated to the issue of strengthening accountability. It stated very clearly that due to the provision of substantial additional resources public accountability is more necessary and that the *'the NHS now needs to demonstrate how resources have been used and how performance has improved, both nationally and locally'* (section 10.14). To achieve clearer public accountability a stronger system of inspection for health and social services was proposed. The paper acknowledged that the current inspection system used was fragmented, and so measures to bring together a number of commissions responsible for standards were part of the package. However, it also proposed that Primary Care Trusts would have to publish an annual patient's prospectus with detailed information on standards and services in their area, including how people can get more fully involved if they wish.

Section 11 of the Health and Social Care Act (2001) placed a duty on Strategic Health Authorities, Primary Care and NHS trusts to make arrangements to involve and consult patients and the public in:

- the ongoing planning of services they are responsible for
- developing and considering proposals for change in the way services are provided
- decisions that may affect how those services operate

This policy and practice guidance was intended for NHS Boards and Chief Executives, all responsible for patient and public involvement, Overview and Scrutiny Committees and PPI forums. Therefore, in relation to the mandate, there was a duty to provide evidence of involvement with patients and the public and in terms of scrutiny of the health service, to provide a form of accountability, as detailed in Chapter 2.

The Kennedy Report (Department of Health 2001), which reported on the findings of the Bristol Royal Infirmary inquiry, made statements about patient and public involvement within its recommendations, and stated that: '*patients must be at the centre of the NHS and thus the patients perspective must be included in the policies, planning and delivery of services at every level*' (section 51). The report highlighted the importance of a patient-centred service that addressed the needs of the public with strategic planning at national level and decisions at local level involving the public. It detailed principles, which should inform future policy about involving public and patients in the NHS. These are:

- patients and the public are entitled to be involved wherever decisions are taken about NHS care
- involvement must be embedded in the structures of the NHS and permeate all aspects of healthcare
- patients and public should have access to the relevant information
- professionals must be partners in the process of involvement
- there must be honesty about the scope of the publics involvement as not all decisions can be made by the public
- there must be transparency and openness
- mechanisms for involvement should be evaluated for effectiveness
- public and patients involved must have access to training and funding to allow them to participate
- the public should be represented by a wide range of individuals and groups and not by particular 'patient groups'

The format of the patient and public involvement forums within Trusts mirrored extensively, in principle, these report recommendations. The priority was for the public to be *'on the inside'*, rather than represented by some organisation *'on the outside'*. Other high profile cases, such as that of Harold Shipman, the general practitioner found guilty of murdering patients (Shipman Inquiry 2001) and revelations about unauthorised organ retention at hospitals at Bristol, Alder Hey and elsewhere (Kennedy 2001), fuelled demands for greater health service accountability to patient's (Irvine 2004), as detailed in Chapter 2.

In Strengthening Accountability (Department of Health 2003) the government made clear that, the context of Section 11 of the Health and Social Care Act was more about changing attitudes within the NHS and the way the NHS works rather than laying down rules and procedures. It was intended to lead the ways of working in the NHS that would strengthen accountability to local communities, speed up change and create patient responsive services. NHS organisations were required to meet the patient and public involvement targets set out in the Priorities and Planning Framework for 2003-2006. This framework identified the priorities that organisations needed locally. One of the priority areas listed was improving the patient experience. The objective for that priority is that:

'The NHS will be transformed through better engagement with patients, the public and staff. By regularly seeking out and acting on local feedback, the NHS will create patient responsive services that people perceive are improving' (p.19)

One of the targets for achieving this is to:

- strengthen accountability to local communities through improved engagement with them, as evidenced by annual patient forum reports to the Commission for Patient and Public Involvement in Health, and annual publication of the patient prospectus covering local health services

Strengthening Accountability stated that in demonstrating their commitment to this new duty the expectation would be for Trusts to complete the following:

- to carry out a baseline assessment of current work
- to develop a strategy for involving patients and the public

- to make sure there is a planning process for patient and public involvement that brings together the feedback from the Patient Advice and Liaison Service (PALS), patient's forums, overview and scrutiny committees, complaints and the annual patient's survey

The paper also recommended that Trusts should have arrangements in place locally to take account of the baseline assessment and that patient's forums and Overview and Scrutiny Committees are involved immediately on the priorities for involving and consulting the local community. The paper also advised that patient and public involvement would be routinely assessed and that evidence would be required to support processes.

'Involving and consulting' had a particular meaning in the context of government and Section 11. It meant discussions with patients and the public on their ideas and their experience, the organisational plans, changes to services, what the public want from services, how to make the best use of resources and so on. The paper also stated that part of the involvement and consultation process should be to discuss the most appropriate ways of further involvement for harder-to-reach groups who may be affected by proposed change. Indeed, a key aim of the forums was to be representative of the communities they served (Grant, 2003): one size and type of PPI Forum would not fit all.

The original deadline for PPI forums was set to coincide with the disbandment of the Community Health Councils (CHC's) in September 2003, although delays meant PPI forums were not in place until December 2003. In a government Health Select Committee report (HMSO 2003a) concerns were raised on the December start date, the committee urging the government to consider extending CHC's period of operation to July 2004 to allow a period of overlap between CHC's and PPI Forums. Patient and Public Forums were only one part of the duties taken on under the umbrella of the Commission for Patient and Public Involvement in Health. There would also be a new Independent Complaints Advocacy Services, Overview and Scrutiny Committees in local authorities and Patient Advice and Liaison Services (PALS), although the latter would have input into the forums.

The NHS had been undergoing changes at this time, for example, changes to the working practices and contractual arrangements within General Practice, which had implications for professional hierarchies and power, by removing practitioners' autonomy over the way they provided services. It is clear however that the notion of a more patient centred service must include more choice, control, and improvements between professionals and patient relationships, but in reality, the focus of public involvement is predominantly in policy and the planning and delivery of services (Elwyn et al 1999). As detailed in Chapter 2, (Conclusions), patient and public involvement is defined by the relationships between the professionals, organisations, individuals and communities. Involvement of patients and the public will only prosper if there is professional willingness to actively develop these relationships, to move away from the security of professional power to a more meaningful engagement with the values, interests and needs of the patient/user being explicit in the development phase. These relationships are considered key factors to determine within this research.

Foundation Trusts are another step and change in giving greater freedom to NHS organisations. The idea is to move from an NHS controlled nationally, towards an NHS where standard inspections are national but where delivery and accountability are more localised. Foundation trusts have greater operational freedoms and unlike present NHS

Trusts are able to retain and reinvest financial surpluses for the benefit of patients. Clearly, this gives opportunity for innovation in managing and delivering services to patients. The Health and Social Care (Community Health and Standards) Act 2001 established NHS Foundation Trusts as independent public benefit corporations modelled on co-operative and mutual traditions. Foundation Trusts exist to provide and develop services for NHS patients according the NHS principles and standards and are subject to NHS inspection. Transferring ownership and accountability from Whitehall to the local community means that Foundation Trusts are able to tailor their services to meet the needs of the local population. The government's purpose in establishing NHS Foundation Trusts was to:

- devolve more power and responsibility to the local level and improve services for patients by incentivising innovation and entrepreneurialism
- devolve accountability to local stakeholders including NHS patients and staff
- support patient choice by increasing the plurality and diversity of providers

(Foundation Trusts are detailed further from page 130).

British Local Authorities have also employed an increasing number and range of public participation initiatives (Lowndes et al 2001). These are in the context of New Labour's '*democratic renewal agenda*' and as the result of longer-term processes of innovation in local government. Central government is imposing new requirements upon local authorities to consult with the public – over service delivery, over securing community '*well-being*', on new political management requirements and as a criterion for achieving 'Beacon' status (DETR 1998). Leading local authorities have also developed innovative methods of consultation and deliberation – including websites, citizen's juries, panels and community planning (Lowndes 1998a).

Lowndes et al 2001 completed a case study on local authority officers and members which documented the growth and diversity of activity designed to enhance public participation. The paper also showed that such initiatives are not always well supported and often fail to influence final decision-making. Lowndes et al (2001) also completed a separate paper probing the view of the citizens themselves about the prospect and reality of public participation. A better understanding of citizen's attitudes and behaviours was considered necessary to address the real problems of apathy and social exclusion that often bedevil participation initiatives.

In Choosing Health (Department of Health 2005), the government highlighted new forms of community voice and action in promoting action on health inequalities, with the emphasis on working in partnership with communities, local business, local government and volunteers. In 'Our Health Our Care Our Say' (Department of Health 2006), the government emphasised the commitment to changing attitudes in the NHS and emphasised the review of patient and public involvement.

The Conservative government also launched consultation on a new policy to involve patients and the public in decisions about the NHS during 2006. 'Health Watch' was intended to be an independent national body with statutory powers to represent patients and monitor health services. The body would have a role in handling complaints, contributing to public debate and engaging the expertise of the voluntary sector. Overall, the mechanism was intended to represent and promote the interests of patients.

In mid 2006, the government published 'A Stronger Local Voice', which set out a framework for creating a stronger local voice in the development of health and social care services. This document followed on from a consultation exercise and Expert Panel recommendations in April 2006. The Department of Health established the expert panel to conclude the review on patient and public involvement. The panel was chaired by, the Department of Health's Director for Patients and the Public and the Chief Executive of the National Consumer Council. Its task was to make recommendations that took into account the evidence collected from the review and from a range of witnesses such as the Commission for Patient and Public Involvement in Health. It was also meant to build on findings from patients' experiences and user involvement in health and social care, plus the specific work of patients' forums and Overview and Scrutiny Committees. Five forum members, nominated from Forum reference groups attended as individuals rather than as formal representatives. The intention for the new arrangements are to build on the work of the patient forums and the involvement activities of individuals, groups and networks and to strengthen and widen the way in which people's views are gathered, listened to and taken account of when health and social care services are planned, developed and commissioned (Department of Health 2006).

From these processes, the government introduced the Local Government and Public Involvement in Health Bill (2007). Included in this Bill was the proposal and framework for introducing the planned new concept of Local Involvement Networks (LINks), their specific future arrangements with Overview and Scrutiny Committees and the new duties placed on commissioners to respond to what patients and the public have said. The LINks proposals are not without controversy due to their perceived lack of independence and differing powers with regard to inspection (Carlisle 2007). A (2007) Health Select Committee Report raised concerns about the mismatch between ambition and resources for the proposed reform. Results from this research could be useful for consideration by these new groups, to continually build and develop patient and public involvement.

The following sections detail information on the patient and public involvement forums the Commission for Patient and Public Involvement in Health and the Forum Support Organisations. Other organisations with links to patients and the public are also reviewed.

3.3 The Formal System of Patient and Public Involvement in the NHS

3.3.1 Patient and Public Involvement Forums

As previously stated patient and public involvement forums took over from Community Health Councils in December 2003. The government initially envisaged that patient groups would be established in all NHS and Primary Care Trusts. It is also important to mention that many of the Primary Care Trusts that participated in this study also had their own in-house patient groups.

During the passage of the NHS Health and Social Care Act (Department of Health 2001), the government agreed to establish additional groups, initially called patients' councils, intended to co-ordinate patients' forums and to pursue issues affecting more than one trust or primary care trust (Baggott 2005). However, this format changed prior to the general election (Department of Health 2001a) and due to concerns over lack of co-ordination, the government accepted that:

- forums would have a statutory duty to co-operate with each other
- Primary Care Trust patients forums would have an extended role, due to the commissioning role within primary care
- a proportion of Primary Care Trust forum members would be drawn from other Trust forums in their area
- that the support networks (Forum Support Organisations) would be the responsibility of a new statutory national organisation (ultimately named the Commission for Patient and Public Involvement in Health)

The forums were subsequently renamed patient and public involvement forums (PPI Forums) to reflect their wider role in representing the community. It is important to have a distinction between representing (advocating for) and representativeness (seeking ethnic balance) within the groups. Representativeness is a difficult concept and one that is very difficult to achieve, indeed authors like Lowndes et al (2001) state that it may be unrealistic to expect this balance, particularly early on in the development of a group. However, it is important to continually widen the processes to include new groups of citizens.

The Forums are created as statutory bodies under the 2002 NHS Reform and Social Care Professions Act, to act as a vehicle for raising awareness to the needs and views of patients and the public. The PPI forum rules and regulations are ultimately covered under two National Health Service statutory instruments (2123 and 2124), which relate to membership, procedures and patient forum functions. The Regulations particularly relevant to this research are discussed where appropriate within this chapter and again within the results sections, Chapters 5 and 6.

The forums were intended to have a number of initial primary roles, which included:

- obtaining the views of patients about health services and making recommendations and reports to the NHS about these
- making recommendations on the range and day to day delivery of health services
- influencing the design of and access to NHS services
- providing advice and information on services to patients/public
- monitoring the effectiveness of local Patient Advice and Liaison Services (PALS)

The PPI forums were originally formed as independent groups of local lay people who could represent, monitor and review health services. The PPI forums and Commission's independence from the NHS and government was seen as a key change and development (CPPIH 2003). However, Baggott (2005) commented that a general lack of independence was evident in view of the political and resource constraints applied. Hogg (1999) commented that even though patients were becoming more assertive they still lacked political leverage.

With greater inspection rights than Community Health Councils (CHC's), including over GP surgeries and the private sector, Primary Care PPI forums were also intended to have the freedom to take up issues. This meant not only with their own Primary Care Trust but also with the Commission and anyone else they think is appropriate, for example local MP's, the media and a raft of local agencies which had responsibility for public health. The forums could also refer matters to the relevant Overview and Scrutiny Committee and any other body it thought fit. In addition, NHS Trusts, Primary Care Trusts and Strategic Health Authorities were required to provide information to patient's forums on request (subject to confidentiality) and both NHS and Primary Care Trusts were required to respond to patient's forums reports and requests.

The Primary Care Trust PPI forums also had additional responsibilities:

- To promote, encourage and support patient and public involvement in health
- To represent patients and public views on matters affecting their health
- To provide advise to the NHS and other bodies on public involvement

PPI Forums were established to have a statutory minimum membership of at least seven members although the Commission for Patient and Public Involvement in Health actually had higher recruitment targets, as set out in the member handbook (CPPIH 2004). A forum member's term of office was determined for a period of between one and four years and was agreed by the forum member and the Commission at the time of appointment.

Originally, the NHS plan envisaged membership being drawn from patient's organisations' and former patients but the composition was modified to include the public as well as patients and carers. In the case of Primary Care forums, they were required to have local residents making up the majority of members with at least one representative from each of the Hospital Trust forums in the area. This, in addition to the rules requiring all forums to have one representative of a patient or carer voluntary organisation and at least one former or current patient (Baggott 2005).

It was recommended that the PPI forums members appointed a chair and deputy chair (CPPIH 2004), although this was not compulsory. However, given that the forum groups held formal meetings in public this role could have been important, particularly if appointed chairs had previous leadership experience and understood organisational rules such as membership, finances and public speaking. Bennis (1998) commented that leaders are people, who are able to express themselves fully. "*They also know what they want*", he continued "*why they want it, and how to communicate what they want to others, in order to gain their co-operation and support*". Some commentators (Doyle et al 2001, Wright 1996) have searched for classical traits and behaviours in leadership where leaders: become the focus for solutions, give direction and have vision and special qualities setting them apart. This view of leadership may sit quite comfortably with some NHS organisations but would not necessarily satisfy the choices of voluntary groups.

PPI Forums were encouraged to hold their meetings in public. The Regulations stated that meetings that discussed certain major issues had to be held in public, with advance notice given. PPI forums were not obliged however to work in a standard committee structure but were meant to be able to influence the statutory body, the Commission for Patient and Public Involvement in Health, in its decision making processes. With all these conditions to satisfy, and with all the 572 forums needing at least seven members, recruitment was a challenge (Baggott 2005). In turn, this led to delays in establishing the forums and recruitment and retention became an ongoing problem, with a reported eleven per cent of forum members resigning within the first six months of being appointed (Gaze 2004). These concerns led to discussions about amalgamating forums in primary care trust areas and changing their focus to monitoring NHS services and representing the public's viewpoints on services. Ultimately, and due to Primary Care Trust amalgamations during 2006, most Primary Care PPI forums did also amalgamate following these geographical and population changes.

There were no statutory details on hours or time commitment within the Patient Forum Regulations (2003) but the Commission for Patient and Public Involvement in Health advised members in the forum handbook (2004) that they were expected to spend between two and three hours per week on forum activities. Given the recruitment and retention difficulties, the amount of hours appeared unrealistic and more detailed discussion is addressed within the section on recruitment (Chapter 5, from page 201) and time commitment in relation to activities (Chapter 6, from page 248).

Volunteers were the key element to patient and public involvement forum groups. Clearly many people are motivated by a genuine concern to help others and to improve the quality of life not just for themselves and their families but for the wider community too. Volunteering can strengthen communities and help people to learn and care about the wider society and democracy of which they are a part. Etzioni and George (1999) promoted the development of a different relationship between the public sector and the public. They suggested an alternative mechanism for the delivery of public sector services based on a successful partnership between voluntary sector organisations and the State. In Britain, these policies have been apparent in recent legislation, formally recognising the work of carers of mentally ill and elderly people, whether they are family, friends or relatives (Carers and Disabled Act 2000) as well as the high profile promotion of user involvement in healthcare within the numerous White Papers mentioned previously in this research study.

Voluntary and community organisations often complain of barriers, which stop them being able to compete effectively with the private sector for the provision of services (Martin 2005). The Department of Health clearly wanted to see more Primary Care Services run or influenced by charities or other not-for-profit organisations, but are the voluntary sector organisations up to the job of providing services efficiently and to the highest standard? The Commission provided the funding to secure provision of the administrative support, Forum Support Organisations, and forum members were allowed reimbursement of allowances, such as travel and loss of remunerative time. It was, however, for the Commission to determine the extent of these allowances.

In establishing the PPI forums there was a clear message of intent but only time would demonstrate the effectiveness of the forums. Support for a strong and vibrant voluntary and community sector is an essential component in the vision for the future of health and social care services, and for the wider government agenda promoting social inclusion and building sustainable communities.

3.3.2 Commission for Patient and Public Involvement in Health (CPPIH)

The idea for a national statutory body to represent patients and the public was raised by a previous Labour government in the 1970s, but was not well received by Community Health Councils, who saw it as a threat to their independence (Baggott 2005). The issue returned in the late 1990's as health consumer groups and voluntary organisations sought a stronger national voice for patients and the public. These pressures came at a time when the new system of patient and public involvement required a national focus to ensure consistency, to provide support and to monitor standards.

There was support for a national body (Hogg and Graham 2001) which was publicly funded, had rights of access to information and consultation, and one that was based on regional networks. The other requirement was that it could facilitate support for local bodies to communicate with national organisations, that it was membership-based and that it was accountable to its members, the public and to Parliament (Baggott 2005). The government subsequently proposed the new independent statutory body, the Commission for Patient and Public Involvement in Health (CPPIH).

Following the passage of the appropriate legislation, the CPPIH was established in January 2003. It was an independent, non-departmental public body, sponsored by the Department of Health and reporting to the Secretary of State for Health. It was intended for the commission to oversee and fully promote the system of patient and public involvement. Its responsibility included:

- Representing the views of patients forums and voluntary organisations
- Providing support and co-ordination to patients' forums
- To monitor standards for patients' forums
- To raise matters arising from patients' forum reports and to report matters of patient safety and welfare to the appropriate regulatory body
- To promote public involvement in health service decision-making and policies affecting health
- Advising health ministers about patient and public involvement in health

The Commission also appointed all members to PPI Forums and provided both support and guidance to PPI forums and ICAS. There is published guidance from the Office of the Commissioner for Public Appointments (OCPA 2002) who monitor, regulate, report and advise on appointments to public bodies. The Commissioner published a code of practice (OCPA 2002) covering all such appointments. Consumer representatives appointed to public bodies, including the National Health Service, fall under the OCPA code and non-public bodies are also encouraged to adhere to the principles as much as possible. The general principles to cover all bodies include:

- merit, whereby the overriding principle of selection is based on individuals demonstrating their abilities, experience and qualities to match the needs of the body in question
- that no appointments should take place without independent scrutiny from a panel, including an assessor
- equal opportunities, probity to perform duties with integrity, openness and transparency, whereby the principle of open government is continually applied to appointments, with information provided about the appointments made

The Commission was also meant to establish, monitor, fund and support Patient and Public Involvement (PPI) forums and the delivery of the Independent Complaints Advocacy Service (ICAS). Apart from advising the government on how the PPI system was functioning, it would also liaise with other national bodies and the Department of Health on patient and public involvement issues and make recommendations as appropriate. Concerns were expressed both about this CPPIH remit and its independence given the powers of the Secretary of State for Health over the new body and the Transitions Advisory Board (TAB 2002) expressed reservations and recommended a strict Code of Practice. The regulations stated that CPPIH had to agree their annual work programme and any variations with the Secretary of State for Health and many saw this as a potential veto on its activities, given that this body was meant to be independent and this amounted to a restrictive approach.

The other concern was how the centralised statutory organisation would relate to local PPI forum volunteers and other voluntary organisations. Due to these concerns, a decision was made to source the support for forums to voluntary organisations, many of which were not used to providing these kinds of services in the health sector. These local network provider organisations were renamed Forum Support Organisations and their remit was to provide a secretariat, arrange meetings for forums, help forums to work together and to work with existing local networks and finally to support them in representing the patient and public perspective in health related decision-making (Baggott 2005). The lack of experience in this area, the concerns about the level of resources plus the unclear transfer of matters from Community Health Councils caused a fragmentation of support for PPI forums, which raised further doubts about the effectiveness of this new way forward.

Inevitably, and with most health matters there are always constraints on timetables and funding, and the Commission for Patient and Public Involvement in Health was no exception. It was set a very tight timetable by Ministers and received less funding than proposed which in turn led to difficulties in implementing the change from Community Health Councils to the new patient and public involvement system on time. Research undertaken in 2002 (ACHCEW) concluded that a '*fit for purpose*' level of staffing would need £53 million, which compared with an actual government spend of £30 million on the Commission and PPI forums during their first year. The Forum Regulations, together with the time scales on member recruitment numbers, dictated by the government for December 2003, were not easily met by the Commission. Other authors like (Baggott 2005) advised that budget restrictions were one of the reasons for the recruitment challenges and this is not surprising due to the necessity of meeting the criteria together with the initial volunteer numbers needed to fill the large number of forums nationally.

The Transition Advisory Board (TAB 2002a) advised the Department of Health in moving towards the new system, its own membership included representatives from consumer groups, the voluntary sector and community health councils. A listening exercise (Department of Health 2001a, 2001b) was also undertaken prior to the legislation in the NHS Reform Bill 2001/02.

Ultimately, the focus on the Commission's internal issues meant that the statutory body was quickly abolished in the review of arm's-length bodies (Department of Health 2004). The Commission structure, as detailed, was huge, complicated, and arguably very difficult for the public to understand and easily communicate with.

3.3.3 Forum Support Organisations (FSO's)

Forum Support Organisations (FSO's) were contracted to the Commission for Patient and Public Involvement in Health but were operationally responsible to their relevant Regional CPPIH centre. The south-east area was the biggest region with initially 93 forums and 11 Forum Support Organisations. These numbers indicated that a small regional office (20 staff members) would be incredibly stretched to provide good direct service performance. The intention was for Forum Support Organisations to support and service at least two patient and public involvement forums on a geographical rather than specialist basis using their extensive knowledge of well-developed local networks and their experience of working within their local communities.

There was a tendering process to appoint Forum Support Organisations (FSO) on an initial two-year contract, initial registering of interest, tender invitation, screening, interviews and negotiations until final decisions were made in August 2003, with contracts starting one month later. The FSO's were voluntary or not-for-profit organisations and clearly were given very little security for the future of forums but many voluntary organisations are accustomed to working in this way. The initial three month run-in process was used by FSO's to put together an infrastructure for the start of the PPI forum process in December 2003. The timescales were very tight but were clearly driven by Department of Health targets to recruit forum members by 1st December with no shadow period or overlap, as Community Health Councils had being abolished.

The scope of work for the Forum Support Organisation was envisaged to fall into three broad areas (CPPIH 2003):

- To contribute to the effective operation of forums: to developing networks with other health forums and to facilitate forum access to external information sources FSO's were seen as an important component to the overall communications strategy of the groups in enabling individual patients and the public to connect with other forums and the wider networks of community groups and also to support communication between forums and the Commission, Overview and Scrutiny Committees and other agencies. FSO's could provide guidance to Forums on legislation and regulations but without leading or influencing direction
- To provide training and development opportunities for PPI Forums and forum support organisation staff with the aim of building local capacity for, and

involvement in, informed dialogues, and of developing local expertise in health matters. This could be structured programmes for the group or for individual members improving their contribution to the forum and its ongoing development

- To assist with local recruitment to the PPI Forums (via CPPIH), and to promote enthusiasm for participation in PPI within the community. FSO's were intended to assist forums to examine the diversity and representation of their forum in relation to their geographical area and type of Trust. Also to meet administrative requirements including controlling the use of PPI funds and to work from, readily accessible community-based, local premises

Local performance was directed by objectives and standards set by the regional centre under a performance management process. The Forum Support Organisations were required to comply with the policies and regulation specified in their contract and project outcomes. This included providing annual reports on forum activity and published accounts. If FSO's were not performing, then there was monitoring and review but ultimately the Department of Health had the right to terminate any contract early and secure an alternative supplier if standards were not being met. The Forum Support Organisations were supporting forums during a time of extensive change within the NHS, such as the reconfiguration of NHS and Primary Care Trusts, the development of more choice and diversity for patients and the vision for health and social care services closer to home.

In Kent, the chosen county for this research study, only two FSO's were appointed, covering the total nine Primary Care Trusts forums within this study and the seven other NHS Trusts forums. These were:

- <u>FSO 'A'</u> – a consortia covering eleven PPI forums (seven Primary Care Trust, three NHS Trust plus Kent Ambulance Trust from 2003)

This organisation was newly formed in 2003 and the five Directors of this organisation were formerly Chief Officers of other disbanded Community Health Councils. Although not used to organisational community working, the new organisation felt that they had the experience, knowledge and local networks in health issues to commit to being the required not for profit organisation.

The organisation had a centralised forum office and at the time of this research, had decided to break the forums down into teams (four teams in four patches). They took this approach because their geographical spread was large and their patch team members had knowledge of their own areas and localities, their local health issues, areas of deprivation and the health services provided. Each forum staff team consisted of a dedicated Forum Co-ordinator and Officer directly co-ordinating their respective forums activities.

- <u>FSO 'B'</u> – a consortia covering five PPI forums (two Primary Care Trust and three NHS Trust from 2003)

This voluntary organisation was established in 1965 to provide support to voluntary organisations and community groups in the Kent area. This local organisation provided support, advice, training and networking opportunities for their members. Their overall mission was to promote, develop and support, through partnership, a dynamic and diverse *voluntary and community sector. This group formed a partnership board of organisations from the voluntary sector. Apart from the main organisation, these included two other voluntary care groups and a local mental health advocacy centre.*

This organisation ran a more centralised forum service, with a much smaller team from their office base in a large prominent county town. The organisation supported their PPI Forums until 2006, when during the amalgamation of forums in line with the amalgamation of Primary Care Trust's, the PPI forum contract was given to the larger Kent Forum Support Organisation (FSO A).

Throughout the term 2003-2006, Forum Support Organisation contracts had always been fixed term due to the uncertainties and the proposed abolition of the Commission.

3.3.4 Patient Advocacy and Liaison Service (PALS)

The NHS Plan proposed the Patient Advocacy and Liaison service within every NHS and Primary Care Trust with the objective of resolving queries and concerns raised by patients and their relatives. There was initial confusion about how this system would be implemented across the NHS particularly as the word '*advocacy*' was included in the new title. The title lead to thoughts of an independent or impartial service, when in fact this service was managed and operated by the Primary and Secondary Care Trusts and therefore was not totally independent of the NHS. There were also real concerns that the service would supersede independent advocacy services, which had been created, particularly to support defined areas of the population, such as the elderly. The service was actually renamed as the Patient Advice and Liaison Service to counteract these early concerns.

The main function of the service was defined by the Department of Health (Department of Health 2002). These were:

- to be identifiable and accessible to patients, relatives and carers
- to provide relevant information and help to agree a speedy resolution to any problem
- to act as a gateway to independent advice and to act as a catalyst for improvements to services
- to support NHS staff and provide a seamless service to primary, secondary and social care

In reality the PALS service, following an evaluation in 2006 (Department of Health), provided information, signposting to other services and helps to resolve problems for patients, service users and carers. The PALS teams acted as a resource for staff and a source of intelligence to improve patient services. PALS frequently have a view of the organisation and are used to problem solving, which must enable them an overview of service provision. However, the role is much more about networking and listening, building trust and relationships rather than demonstrating outcomes, particularly around strategic or culture change. The evaluation concluded that there were numerous models of PALS within the health service, with 40% operating single handed within a single Trust, all operating on a range of budgets, reflecting the range of staff levels and seniority of PALS leads. There was also variation within roles with many leads also having the patient and public involvement responsibility, or responsibility for ICAS, patient surveys or expert patient programmes.

PALS have a duty to enable and empower patients and others to use Trust services effectively and provide a conduit between the often uncommunicative Trust systems, often being the last source of hope for people in terms of obtaining support and a response. However, it was noted in the national evaluation that most PALS reports were not usually recorded or analysed systematically (Department of Health 2006). PALS were effective in filtering potential complaints and enabling patients to raise issues in an effective way, which was useful to the relevant organisation. There appeared to be an anecdotal belief that PALS reduced the number of complaints against the emerging context of higher expectations and loss of public trust in health professionals.

3.3.5 Independent Complaints and Advisory Service (ICAS)

The Commission for Patient and Public Involvement in Health was given the initial responsibility for implementing the statutory duty to ensure provision of the Independent Complaints Advocacy Service (ICAS) but in turn delegated this to the Primary Care Trust Patient and Public Involvement forums. Through the ongoing delays in establishing forums fully, ICAS was not in place by the time Community Health Councils were abolished so interim measures were made by the Department of Health, directly commissioning ICAS at a national level (Cole 2003). The service was meant to provide a national health complaint advocacy service delivered to agreed quality standards, remembering that Section 12 of the Health and Social Care Act (2001) placed a duty on the provision of ICAS to assist individuals making complaints against the NHS.

As soon as the Arm's Length Body Review announced that the Commission for Patient and Public Involvement in Health was going to be abolished, the Department of Health maintained its lead responsibility for ICAS and these arrangements have continued at the national level. From April 2006, contracts were awarded to three organisations to deliver ICAS across England; these organisations were the same providers that had delivered the service since 2003, when taking over from Community Health Councils. The new service was designed following an evaluation conducted by MORI. The most significant change to the service was to service delivery, using two distinct but complimentary models dependent on client need.

The first model was aimed at self-advocacy, designed to empower the public to be able to raise their concerns. This format assisted with information, support via telephone or written communication, self-help information and 'third party' professional support from an advice worker. The second supported advocacy model is designed for more disadvantaged or vulnerable members of the public who may need access to more specialist support within the complaints process. As often happens, the people who are going to fall through the net are those people who traditionally have been most difficult to access – the socially excluded. What then will all this mean in terms of the patient and public involvement forums for the future and the plethora of patient groups, support groups, complaint and review committees that are meant to assist the public

3.3.6 Overview and Scrutiny Committees (OSC's)

Health scrutiny could be seen as both a challenge and an opportunity for Local Authorities and the NHS. The government's intention (Department of Health 2003) was that the focus of health scrutiny was on health improvement, bringing together the responsibilities of local authorities to promote social, environmental and economic well-being and the power to scrutinise local services provided and commissioned by the NHS. The overview and scrutiny of the NHS was seen as one element of the Government's drive to strengthen patient and public involvement within the NHS, the other element with the intended connection to effective health scrutiny was the patient and public involvement forums.

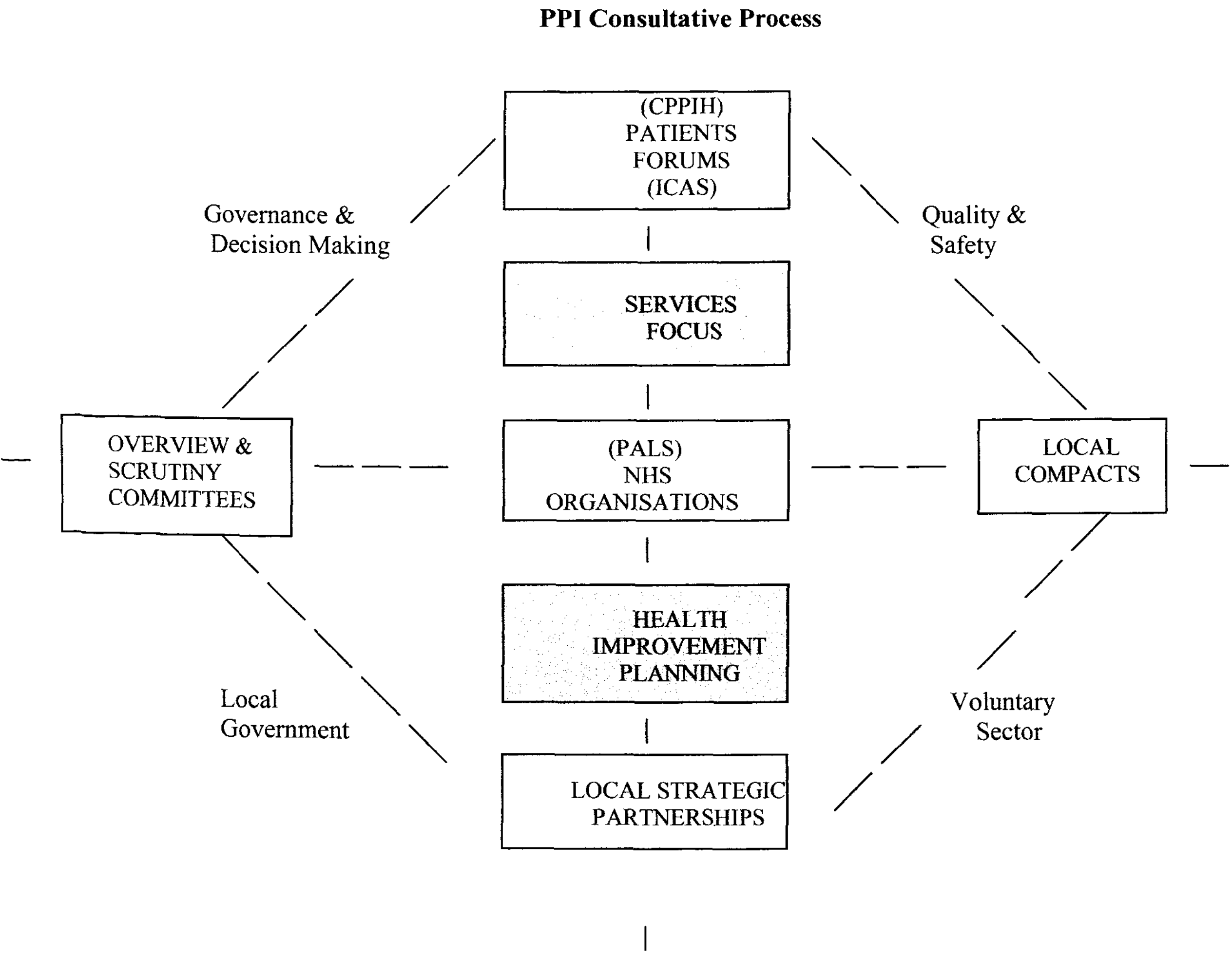
From January 2003, Overview and Scrutiny Committees were set up in Local Authorities with social service responsibilities (County Councils, London Borough Councils and Unitary Authorities), have had the power to scrutinise health services. This contributed to their wider role in health improvement and reducing health inequalities for their area and its inhabitants. NHS organisations are required to consult with OSC's on any plans that would result in major changes to health services. The committees should also look at the way NHS services interact with council services and explore ways that they can jointly provide better health support within their local communities. The OSC's can scrutinise any local health service provided and commissioned through the NHS as well as those provided by local authorities.

Their defined role following the guidance issued in 2003 was to:

- take on the role of scrutiny, not just major change but also ongoing operation and planning of services
- refer contested service change to the Secretary of State
- call NHS Managers to give information about service decisions
- be consulted by the NHS where there are to be major changes to health services

All of the committees are meant to look at the work of the Primary Care and NHS Trusts and the Strategic Health Authority. What defines a '*substantial development*' or '*variation*' to NHS services is not defined in law. However, the guidance on overview and scrutiny recommended that local NHS organisations should aim to reach an understanding or definition with their OSC on this issue and that this should be informed by discussions with other stakeholders, including PPI forums. Many OSC's have agreed frameworks with their NHS bodies in order to reach some form of understanding although clearly this is only one part of the picture in terms of any proposal for substantial development or variation to health services. The diagram below (3.2) illustrates the various strands that were involved from 2003-2006 in the patient and public involvement process.

Diagram 3.2 - Detail of Overview and Scrutiny Committees and other agencies in relation to PPI Forums



3.3.7 Foundation Trusts

The government decided to introduce Foundation Trusts long before the establishment of PPI forums and their formation in terms of patient and public involvement is interesting and needs some explanation. These Trusts represent a change in the history of the NHS in the way that hospital services are managed and provided (Department of Health 2005).

Any high performing Trust running hospital and specialist services, can apply for Foundation Trust status. Although they continue to provide services within the NHS, they are promised greater freedom to run their own affairs and are meant to establish methods to be more responsive to patients and local communities (Department of Health 2002). Foundation Trusts are seen as a vehicle for drawing the public into a more participatory group, in terms of a mutual organisation. Members of the public would participate in elections to become a member of the governing board, although in practice these roles would be very limited (NEF 2004).

Foundation Trusts are established as Public Benefit Corporations - a sort of halfway house between the public and private sectors - and are free from the powers of direction from the Secretary of State for Health, instead being locally accountable with independent regulation. Foundations Trust are independent organisations operating within the NHS to improve outcomes for patients and local communities (Department of Health 2005). Once an aspiring Foundation Trust has proven it can govern itself, it ceases to be under the command of the Secretary of State for Health and is no longer performance managed by NHS Authorities, although is still regulated.

The Department of Health is keen to promote Foundation Trusts as a new form of local public ownership and one that can be improved by exposure to the freedoms and disciplines of the market. The expected benefits of this '*localist*' approach are a greater sense of ownership and engagement of patients, the community and staff in the running of public services and, consequently, an improvement in the quality and responsiveness of services (Blears 2003). Reforms of this type do have an internal logic as the financial strength of the individual organisation can be pursued but conceivably at the expense of other concerns and of competitors within the sector.

Foundation status should allow managers more autonomy. They will not be line-managed by the Department of Health; they will undergo less inspection; they will be able to finance capital programmes; they will be able to retain land sales for re-investment, they can establish private companies and have the ability to pay staff over nationally agreed terms and conditions (Department of Health 2005).

The financial freedoms cover three areas:

- the retention of proceeds from asset disposal – certainly an incentive but Trusts will need to demonstrate that the proceeds will be used to further their public interest mandate
- retention of operating surpluses – under the commissioning system the 'funding will flow to the providers of patient choice', and there seems an inevitability that funding will flow away from unpopular providers

- access to a capital base on financial performance and the ability to meet liabilities by borrowing – the ability to demonstrate guaranteed long term revenue streams will be crucial in deciding on borrowing in private markets and the cost of doing so

The Regulator is tasked to ensure that the membership of the new Trust is representative of the local community, although it is somewhat difficult to understand how this judgement will be made. There is also a duty of co-operation between the Regulator and the Commission for Healthcare Audit and Inspection. This concept therefore represented an attempt to combine some of the advantages believed to flow from devolved decision-making (including flexibility, innovation and local responsiveness) with the retention of a commitment to NHS principles and national standards (Walshe 2003).

It is to be remembered that it cannot be politically, financially or organisationally sensible to attempt to run the NHS from the Department of Health. Foundation Hospitals, in principle, offer a vision of a new model of governance and accountability, replacing the vertical hierarchy topped by the Department of Health and they will have a network of accountability relations within their local communities, local government, other NHS organisations and national regulators (Walshe 2003). Since their introduction in 2004, these Trusts have been developing new governance arrangements, largely independently, guided only by the requirements of legislation – The Health and Social Care Act 2003. Defining what local governance arrangements should look like as they evolve are crucial if the public is to be reassured that these Trust have not simply been handed over to the managers and professional that run them (Lewis 2005).

It is very difficult to say that these new governance arrangements have improved patient care. The argument that it can is based on the notion that increased stakeholder involvement will result in improved services. This may result in different services but whether these will be better is a moot point. The issue must be seen in the context of a range of changes within the NHS and some critics argue that Foundation Trusts will add to the fragmentation of the healthcare delivery system, particularly as the Trusts will be competing for more income at the expense of other acute hospitals and of primary care.

The first Trusts were fully operational when appropriate legislation was passed in April 2004. However, the twists and turns in health policy and a tendency for policy to be set up as the need arises, means that plans have been liable to modification and revision. Notwithstanding this uncertainty, official statements have indicated that hospitals that are currently performing at the highest standard in terms of the NHS performance ratings - of three stars – have applied for foundation status (Department of Health 2002).

Klein (2003) had serious doubts over the proposed internal model of governance. Each Foundation Trust would have a board of governors recruited from members of the public, patients and staff. Those members elect governors with a range of powers over the management of the trust. In turn, this board of governors would choose the Chief Executive and the Non-Executive members of the day-to-day management board. However, *who* are the members electing the board of governors? Anyone who lives locally, who has been a patient of the Trust or who is an employee is eligible to register and vote, however, the actual organisation of this voting is left to the aspiring Foundation Trust. One could hypothesise that the membership would therefore be unrepresentative and skewed towards the above criteria of eligibility, possibly with atypical views about the NHS.

Klein (2004) also discussed the problem of excess of accountability. Foundation Trusts would be accountable to the newly shaped independent regulator who would license them, monitor them and decide what services they should provide and if necessary dissolve them. In the process, the regulator would be able to impose additional requirements on the Trust, remove members of the management board and order new elections. The regulator would also determine the limits of the spending powers and would be informed of audit and inspection reviews. Foundation Trusts would have to answer to the Overview and Scrutiny Committees and would finally be accountable to the Primary Care Trusts for fulfilling contracts. On the provider side these more radical forms of local accountability are now required but overlapping accountabilities could mean conflicting pressures particularly adapting national priorities to local ones.

Interestingly, and in direct relation to this study, a statement from the Department of Health in May 2003, which followed the draft legislation, indicated that Foundation Trusts would not be required to have PPI Forums. Instead, they would be able to 'determine the best mechanism for meeting their responsibility to involve users and carers'. In a follow-up letter to Alan Milburn, the then Secretary of State for Health, Sharon Grant, Chair of the Commission for Patient and Public Involvement in Health expressed concerns at this and highlighted the proposal requirement that Primary Care Trust forums would be given the additional responsibility of monitoring and reviewing the services of the new Foundation Trusts. Ms Grant continued the concerns of the Commission's Board about the damage to coherence of the new system, as the effect would be enhanced as increasing numbers of NHS Trusts are awarded Foundation Trust status.

Under pressure, the government agreed that each Foundation Trust would have to retain patient and public involvement forums and it was intended that the primary care forums should add this aspect as they developed, meaning Foundation Trusts would not be required to have their own separate forum. Now that Primary Care Trusts have combined it is unlikely that Foundation Trusts would require their own separate forums in the future although there would still be a requirement to consult with both local forums and Overview and Scrutiny Committees. Many Trusts are likely to retain existing forums to fulfil this expectation as the role is seen as complimenting the role of the Governors. However, the role differs from the Governors in the area of inspection and the necessity of responding to requests for information and reports.

More recently, there has been criticism with regard to the Local Government and Public Involvement in Health Bill (Mooney 2007), for placing the duty of consultation on providers, as well as commissioners. The Bill stated that all four types of organisation should consult. The NHS Confederation advised that only Primary Care Trusts and Strategic Health Authorities should have to consult on the planning and provision of services and on '*significant proposals*' to change the way services are provided and operated. Their argument was that Foundation and other provider trusts should instead have a duty to involve users. The distinction being here that commissioners need to consult because they are required to develop strategic assessments and providers need to involve patients to obtain feedback on what is or is not working and the latter meant '*a different range of questions*'.

3.4 Conclusions

This chapter has sought to give both an historical and recent context to patient and public involvement in health. It is clear that patient and public involvement has been seen as a key element in recent healthcare reform and many of the government papers referenced in Chapters 1, 2 and 3, (Department of Health 1998, 1999, 2000, 2001) have emphasised the importance for, and commitment to the subject. Many people feel they should be able to choose who to consult or where to be treated and there is considerable demand for more involvement in treatment choices, linked to greater expectation. However, patients have diverse needs and expectations leading to different, and sometimes conflicting, views on priorities (Coulter 2005). By providing information and promoting engagement and involvement, governments have wanted to encourage patients and the public to make informed choices with shared decision-making and self-management in health. The policies, in general, give direction on improving NHS performance and have indicated that the health service would be shaped by public views, the question of how, has unfortunately been left unanswered.

As described earlier in this chapter, public participation in public policy and management can be linked back to the Conservative ethos of the late 1980s and the 1990s, Local Voices, the Citizens Charter and other consumerist measures and the rise of '*user*' movements (Barnes 1997). The Labour government built on this agenda and the Modernising Government White Paper talked of '*responsive public services*' catering for the *'needs of different groups'* (Cabinet Office 1999a). The Social Exclusion Unit (1998a) focussed on the need for better strategies of public involvement as a means of building social capital and overcoming social exclusion. Policies offered several alternatives to increase responsiveness to services, including patient involvement, and giving patients more say in their care and treatment choices, from the Expert Patient Programme (Department of Health 2001) to patient choice, which sought to offer a choice of provider for elective care (Appleby et al 2003).

New Labour's governance literature has highlighted the development of different sets of connections between the state, organisations, patients, the public and other stakeholders. These new forms of connections between the state and the citizen could be viewed as a means of responding to the fragmentation of authority and dealing with the ongoing issue of accountability in complex societies (Newman 2001, Mulgan 1994). Behind these lay concerns about the renewal of institutional trust, improving the policy process and enhancing the legitimacy of government.

Against this government background of high priority, individuals and groups have also formed to protest about poor standards in healthcare, for example, as in the events that led to the Bristol Royal Infirmary Inquiry (Cole 2001). This was one of the key failures, which encouraged and indeed demanded the consideration of more patient and public involvement processes like the PPI forums. As a concept, the NHS has long sought to demonstrate public involvement and patient centred care; and the potential has certainly existed since 1974 with the Community Health Councils. Despite their achievements, criticisms around geographical variation and inability to reflect the diversity of their communities led, in part, to their abolition (Tritter and McCullum 2006), and the deployment of PPI Forums. The forums were initially outlined in the NHS Plan (Department of Health 2001) following extensive media criticism about the governments handling of the NHS. PPI local forums were proposed to represent patients and the public and deal speedily with local problems. A further empirical question identified is how have the PPI forums decided on the health issues to address and how wide ranging were these.

As described earlier, the PPI forums had a national statutory body (CPPIH) and a network of support organisations (FSO's) but the new system was enormous and complicated. There was also lack of clarity around the relationships with other statutory bodies, like PALS, and some Primary Care Trusts had their own forums. This all led to public confusion '*and the greater likelihood that people would lose sight of their purpose*' (Banks 2001, page 5)

There is certainly a fundamental role for health related forums or groups, particularly for people who have little opportunity to assist themselves, whether this be due to constraints of low income, poor living conditions, poor communication or multiple health problems. People who use health services offer alternative perspectives and emphasise different priorities to those put forward by the clinicians. Many people are motivated to volunteer on to groups by a genuine concern to help others and to improve the quality of life not just for themselves and their families but for the wider community too. Lowndes et al (1998) highlighted the gap between the public and '*official*' perceptions on involvement and argued that better techniques are necessary to communicate the aim and scope of involvement and to give feedback on outcomes. Patient and public involvement must continue to form an increasingly important part of the strategic direction of health care organisations and to be effective, requires commitment to translate involvement into effective action. Health care organisations need to consider how to sustain patient and public voices in all their business, decision making and looking ahead. Perhaps the

National Health Service will only lose its fear of openness if it risks openness – and welcomes other voices in.

However, there is still a fundamental necessity to have some continuity to progress and develop sufficient expertise within any established lay group or organisation. There is always scope for development and change, but it is easy to lose momentum and lose lay individuals that have developed ideas and terminology over time. Any future government changes to patient and public involvement forums must build on the valuable work developed so far. The future of patient and public involvement is discussed further within Discussion and Conclusions, Chapter 7. The data from this research can only add to the debate for future patient and public involvement development. A wide range of methodologies were considered and used in collecting this research data. The rationales for these are discussed in the following chapter.

CHAPTER 4
METHODOLOGY

4.1 Introduction

This chapter sets out the choices of method that have been made to specify, collect and analyse data to address the questions posed in the previous chapters about the establishment and operation of the Primary Care patient and public involvement forum groups. The study sought to identify:

- The composition and profile of Primary Care PPI forums
- How the PPI forums were constituted, their activity and support
- How the PPI forums related to Primary Care Trusts and other organisations
- In what ways the PPI forums represented their communities

These questions concern on the one hand, the composition of the PPI forums and specifically the profile of the forum members and whether, or in what senses, forum members were able to represent their communities. On the other hand, forum constitution, process and activity, including the establishment of working relationships with other organisations, forum expectations and finally, the implications for future policy.

Research into PPI forum groups, and specifically into Primary Care PPI forums, has been limited. Whilst the process of establishing PPI forums providing comprehensive coverage of NHS organisations was a major enterprise for the Commission for Patient and Public Involvement in Health over a period of several years, there have been few reports and little examination to the outcome of the process.

Two '*levels of analysis*' have been indicated: firstly, the individual forum member; and secondly, the forums aggregated as an organisation. Profiling of the forum membership at individual level, in terms that included the age/gender, backgrounds, and experience of members is an important first step in understanding the character and early operation of the forums. In particular, it responds to questions about the types of individual that might volunteer to represent their community, and their right to involvement in health service decision making and scrutiny. Data about the demographic characteristics of individuals, their experiences of involvement, recruitment and representation were collected, firstly, through a questionnaire survey of individual forum members, and secondly, to develop a greater depth of understanding, through an interview process.

The second (organisational) level of analysis was addressed by aggregating the data about individuals and by obtaining additional data about the character of each forum group as a whole. This examined how the PPI forums had started to operate and gave indications to each forum group in action and their expectations for the future. Data from the member interview process was supplemented by interviews with representatives of the organisations directly involved with the forums, the Commission for Patient and Public Involvement in Health, the Forum Support Organisations and the respective Primary Care Trusts. Finally, data was collected from annual report documentation and some observations of PPI forum group meetings.

4.2 Comparative Case Methods

A number of strategies for inquiry were potential candidates for this research study (these are discussed in more detail on page 147, (quantitative and qualitative choices). As examples, observational research methodology aims to adjudicate between designs with fundamentally different logics of inquiry; the social survey is focussed on understanding patterns across individual behaviour and attitudes; ethnographies focus on a particular phenomenon and seek to present its complex and particular character authentically; and case and comparative case studies focus on the relationships through time, between complex phenomena and their contexts, seeking to illuminate relevant similarities and differences between them.

Alber (1995), in setting out a framework for comparative study in social services, identified that much comparative research tends to be either narrative historical monographs, or sweeping statistical comparisons of quantitative aggregate data. This study has therefore adopted a design, which combines strategies. It uses a questionnaire survey method to gather data about individuals in PPI forums; but the research is not solely concerned with the individual volunteer. It is also interested in the aggregated and organisational character of PPI forums. Focusing on a small number of PPI forums, it therefore also presents cases of the establishment and operation of PPI forums that are amenable to comparison within, detailing an account of the implementation of PPI forum policy in one geographical and administrative area – a Strategic Health Authority. The design seeks to provide, by contrast, a picture of PPI forums resulting from a sample survey of individual forum volunteers, a comparative study of PPI forums, which has resulted from a study of the forums as wholes, and a case account of policy translation and implementation in one area of the United Kingdom.

Comparative case research has a main aim to '*understand and explain the ways in which different societies and cultures experience and act upon social, economic and political* *changes'* (May 1993, p.153). As case study methodologists have noted, the case study, as a research method, focuses on the circumstances, dynamics and complexity of a single case, but commonly incorporates other levels of analysis – cases within cases; or surveys within cases. The approach often links qualitative and quantitative data, studying the subject within their natural settings and comparing, therefore, both phenomena and contexts. Where the method is used to examine a number of cases, the numbers are generally small so that the cases can be explored in-depth, whether retrospectively, currently or over time. A variety of methods are commonly used, such as interviews, information from records and observations. For this study of PPI forums, ultimately, the comparative case study approach offered both a practical and effective methodology through which to collect and analyse relevant data.

There are a range of other perspectives and approaches (Denzin and Lincoln 2000), and numerous typologies of case design, from a relatively simple conceptual mapping of a case to the complex multiple variations suggested by de Vaus (2001). However, three popular intellectual positions were finally considered in assessing the preferred approach of comparative case study (Yin, 1994, 2003; Stake, 1995; Miles and Huberman, 1994).

There are many warnings for the researcher attempting comparative research (Clarke and Kurinczuk 1993). Not the least is the need to balance the desire to seek universal explanations across different contexts, particularly with the increasing complexity of political and social life. The approach adopted by Yin (1994), searching for empirically based explanations, is to use case studies to test theories or hypotheses in a deductive or *'top-down'* way, using various methods of data gathering and in particular interviews and documentation. Yin (2003) sets out a model of the case study that has a '*mechanical'* nature '*rather than struggling with a more fluid, though potentially more creative, reporting structure*' (p.32).

Stake's (1995) more inductive approach, sees case studies as less theoretically driven, using '*bottom-up*' searches for understanding by building hypotheses, more concerned to select a case with the potential to reveal contextual detail and dynamics, rather than, but not to the exclusion of, systematically framing it in a comparison with others. There are some central features of Stake's approach, which are helpful to consider with relevance to this research study. Firstly, the notion of context might include micro events in and around a meeting or the physical climate, which could illuminate aspects of social action. Secondly, Stake also considered the distinction between interviews and methods, which rely solely on reported events and those, which are informed by other additional methods, for example, the researcher's observations of events. Finally, Stake considered the importance of '*self challenge*' where the researcher tries to demonstrate their readiness to be surprised, even proven mistaken, and discusses the possibility that the search for qualitative data may confront the researcher with a wide spectrum of opportunity. Stake also suggested that the report of a case study should follow three stages: a chronological or biographical description of the case, the investigators approach to understanding and investigating the case; and a description of each, in turn, of the major components of the case.

Both Yin (2003) and Stake (1995) are interested in explanation and understanding and in the causes and nature of social phenomena but differences arise from the extent to which they '*frame*' or direct the cases under study (Scott et al 2005). Both research approaches involve the same bundle of characteristics – assumptions, design, data production, analysis and dissemination, both have produced qualitative case studies and are interested in the worlds of policy and practice.

The approach to qualitative data analysis of Miles and Huberman (1994) was also reviewed. They describe a case as a phenomenon occurring in a bounded context. The case in this context is the unit of analysis, with the case having a focus or '*heart*' with a somewhat indeterminate boundary defining the edge or outer limits of the research. They argued that multiple case researches offered the researcher a deeper understanding of processes and outcomes and more opportunities to test hypotheses. They stated that the highest priority is in the creation, testing and revision of simple, practical and effective analysis methods. Comparative case studies can demand extensive resources in terms of time, particularly for the independent research investigator (Yin 1994). The task facing any case study researcher is certainly more complex than amassing individual clues; it is also about connecting the data to the context and the process of interpretation. This can be approached in different ways or in the belief that '*there is much art and much intuitive processing to the search for meaning*' (Stake 1995, p.72).

The real strength of the case study approach is not necessarily to access more information but to access a variety, in terms of the kinds of information. Each has bearing on the phenomenon through which to add to both understanding and confidence in interpretation. The replication approach framework for multi-case studies (Yin 1994), illustrated in the following diagram (4.1 next page), is therefore well suited.

Diagram 4.1 – Yin's Replication Approach for Multi-Case Studies (1994)

Define and Design	***Prepare, Collect and Analyse***	***Analyse and Conclude***
Develop theory		
Select cases	*Conduct 1st/2nd case studies*	
Design data collection	*Write individual case reports*	*Draw cross-case conclusions*
	Conduct remaining case studies	*Modify theory*
	Write remaining case reports	*Develop policy implications*
		Write cross-case report

This useful framework suggests that the initial step in designing the study must consist of theory development, and that case selection and the definition of specific measures are important steps in the design and data collection process. The latter stages of the framework were adapted to provide an overall comparative account.

In summary, the starting point within this research was a conceptual mapping of relevant characteristics of the case at two separate levels – the individual forum member and the forum group (organisational) level. This pointed to the evidence required to construct each case; firstly, to give an account of the general experiences of individuals within the patient and public involvement forum system, and secondly to provide an aggregated account of the forums, in action at the organisational level.

4.3 Quantitative and Qualitative Choices

Qualitative research and quantitative research are usually represented as two fundamentally different paradigms through which to study the social world (Bryman 2001, Brannon

2004). Quantitative approaches are usually associated with a positivist approach Positivism assumes that there is a single objective reality, that it is possible to observe and measure social phenomena, using the principles of the natural scientist to establish and test a reliable and valid body of knowledge (Bowling 2002). Data, usually collected through highly pre-structured instruments, is commonly expressed in formal, statistical language. It is common for quantitative survey methods to be used subsequently to assess how convergent or variable the situations or organisations studied are in terms of specified characteristics.

Qualitative research, by contrast, is aimed to study people in their natural social settings and to collect data that has apparent significance within the context in which it is gathered. Mason (1996) described this as a philosophical position that is essentially 'interpretivist', *'in the sense that it is concerned with how the social world is interpreted, understood, experienced or produced'* (p.4). Patton (1990) stated that qualitative methodologists, "*attempt to understand the multiple interrelationships amongst dimensions that emerge from the data without a priori assumptions*". The focus is on the meanings that the people in the study attach to their social world. Qualitative research describes in words rather than numbers the qualities of social phenomena through observation, interview, diary methods, life histories and focus or group techniques.

Patton also discussed the qualitative quantitative debate and concluded that it is certainly possible and often desirable to combine approaches. Patton stated that quantitative data identify areas of focus; qualitative data gives substance to those areas of focus. What did people really mean when they made a particular answer on the questionnaire? What elaborations can they provide of their responses?

Figure 4.2, below, sets out a simplified version of Patton's (1990) design where a quantitative element points the fieldworker to phenomena of importance, the qualitative section allowing more depth of understanding to how things work and the final quantitative stage is designed to test some resulting, perhaps competing hypotheses.

Figure 4.2 – Patton's (1990) Quantitative/Qualitative Design

QUANT …………………	*QUAL ……………………*	*QUANT*
(initial survey and historical data)	*(fieldwork - issues of importance from initial data)*	*(test results)*

Miles and Huberman (1994) also set out designs linking the use of both qualitative and quantitative data to develop both a greater depth of understanding and also to assist the researcher with issues of reliability and validity (discussed in more detail from page 182). Their continuous linkage design (Figure 4.3 below) involves an integrated collection of both quantitative and collective data, as needed, to understand the case in hand.

Figure 4.3 Miles and Huberman Continuous Quantitative/Qualitative Design (1994)

QUAL (continuous, integrated collection

………………………of both……………………………

QUANT kinds of data)

The quantitative data can help with the qualitative side of this inquiry by finding a representative sample and then locating further respondents. It can also help during data collection by supplying background data, obtaining information, which could have been overlooked, and for analysis purposes could verify qualitative findings. Qualitative data, by contrast, can assist the quantitative side of this study, during the design, by assisting with the conceptual development and instrumentation, and in analysis; it can help with validation, clarification and illustrating quantitative findings. Qualitative data can therefore put flesh on the bones of quantitative results, bringing the results to life. This opens up the possibility of researching in a pluralistic way, drawing on different methodological traditions. Miles and Huberman (1994) state that such '*methodological triangulation*' allows evidence gathered in more than one way to be combined to give a more precise and illuminating picture.

Some authors recommend the use of triangulated methods to enhance the validity of research findings. The aim of triangulation is to draw on the particular and different strengths of various data collection methods, and to use different forms and sources of data as crosschecks, one on the other. Denzin (1989) argued that triangulation elevates the researcher '*above the personal biases that stem from single methodologies*'. By combining methods in the same study, observers can seek to limit deficiencies that can flow from one method. Research using relatively small numbers of cases, will often benefit from a triangulation approach that allows extensive exploration (Bowling 1997) or a '*structural corroboration*' of data (Pepper, 1942).

One issue that had been raised in considering the research design and choice of data collection techniques, concerned the difficulties that might be encountered in gaining access to the forums and to forum members. The initial methodological design and considered choices for this study centred on a questionnaire survey and semi structured interviews (see following discussion). However, given the potential difficulties of access, other, unobtrusive methods - ways of collecting data that minimise the extent of interaction required to undertake the research – were also considered.

First, questionnaire survey methods were considered in this research design as a means of collecting information and statistics in a more cross sectional way from a sample of the population of interest at one point in time (Bowling 2002). Questionnaires are widely used in health research, although this is often for more financially viable options when conducting postal questionnaires with large geographically dispersed populations (Edwards et al 2002). These authors argued that the questionnaire survey method is well suited to delivering the objective of collecting factual, attitudinal and/or behavioural data. In the case of the PPI forums in this research, initial access to a sample of members, using a standardised format to gain information on personal, factual and attitudinal data was an important first step, particularly as it followed a lengthy process of contact, and individual presentations to each participating group. The questionnaire survey gave important initial information on the forum profile and constitution.

Secondly, Grbich (1999) stated that the aim of conducting interviews is to gain information on the perspectives, understandings and meanings constructed by people regarding the events, or experiences of their lives. Bowling (2002) pointed out that the interview process measured facts, attitudes, knowledge and behaviour. Silverman (2005) stated that interviews have an important part to play in research, in providing facts, attitudes and experiences, particularly in areas like health, which affect us all. All of these points were relevant and important to consider in this study. The interview process in this research allowed more in-depth data on Forums to be obtained from the participants of the questionnaire survey. In particular, this methodology allowed for inquiry into the important questions of organisational relationships, community representation and member recruitment and retention experiences. All survey participants were encouraged to become part of the interview stage, with the researcher constantly mindful of establishing rapport to enable a free flow of information and communication.

Thirdly, May (1993) defined *document research* as a record of written, audio or visual images which can be a source '*of*' or '*for*' research. Silverman (1993) considered records as a '*potential goldmine for sociological investigation'*. Conversely, Bowling (2002) argues that documents cannot be regarded as completely accurate representations of the phenomenon of interest, although within limitations, they could be valuable sources of data. Completion of an annual report was a statutory requirement placed on PPI Forums and these were viewed as an important source of information that could suggest activities, needs and priorities of the groups. Other documentation about the PPI forums was very scarce so the documentary data, although important, was intended for use more in a limited, confirmatory capacity rather than as a primary source of information, particularly around work plans, detail on activity and forum meetings.

Fourthly, the possibility of observing group processes was considered another important choice as the social practices and social interactions within the forums from observed meetings could be revealing. Authors like Grbich (1999), define observational research as a technique of unobtrusive data collection, which involves the researcher spending time in an environment to understand the meaning constructed, making sense of everyday life experiences. Bowling (2002) advised that observations are a tool to understand more than what people say about (complex) situations and can help to understand these situations more fully. The history of observational techniques were also briefly described by May (1993). In particular, and with reference to this research, that the observations could provide an inside view of the member and group meetings, activities and relationships (including any work with and within the communities which the PPI forum members represented).

Finally, other research methods, for example focus groups, were also reviewed in some detail. This method was however, not seen as feasible given the small amount of respondents in some forum groups. Although there were forty participants overall, the respondent numbers were not equally divided amongst the participating groups. Some authors have discussed the guidelines for conducting focus group research (Silverman 1993, Bowling 2002) and advise that group dynamics can stimulate discussion in greater depth but that groups need careful balance and should have a minimum of six participants. Of course, the overall study participant numbers could have been amalgamated, but confidentiality could not have been maintained in this setting and this had been ethically agreed. Kitzinger (1996) advised that although group processes can help people to explore their views, confidentiality is not obtained in group settings. The overall Kent forum membership would also not necessarily have known each other and apart from the confidentiality issues, this was considered a potential inhibiting factor for some respondents.

In conclusion, interrelated processes of questionnaire survey, interview, documentation and observation were chosen to develop as multilayered and informative picture of both individual forum members and the forums as organisations. A research study that included a social survey and comparative case analysis, using multi methodology, provided an account of the implementation of PPI forum groups.

4.4 Data Collection

4.4.1. Selection of Sites and Access

The sites for this research study were the nine inaugural Primary Care patient and public involvement forums within the Kent and Medway Strategic Health Authority area. Primary Care Forums were ultimately chosen in this research for two reasons: Firstly, the Primary Care PPI forums had a wider role in encouraging patient and public involvement, including Primary Care Trust and Strategic Health Authority consultations. Secondly, the researcher worked in the Primary Care field and had a particular interest in this part of the health service, which is also an area of ongoing government national health philosophy in transferring the emphasis away from hospital-based treatment towards community-led care.

The locations were chosen as they represented a mixture of town based, rural and coastal communities with differing sizes of population and differing health priorities (Kent Strategic Health Authority and Primary Care Trust annual reports, 2005/06). Background characteristics of the geographical areas, including population numbers and Primary Care Trust information is indicated below, (table 4.1), which gives a flavour of the numbers involved in each Primary Care PPI Forum area.

Table 4.1 – Background information on population numbers and PCT budgets/performance for each Primary Care PPI Forum area 2005/06 (sourced from Primary Care Annual Reports and NHS Primary Care websites)

Group	**Information**
Group A	*The population of this Primary Care Trust area was approximately 104,000 and the area was probably the least deprived, following major housing and industry re-development. The local Primary Care Trust operated on a budget of £92 million and had a two star performance rating.*
Group B	*This Primary Care Trust area provided healthcare for a population of about 174,000 people and had a budget of £146 million. The local Primary Care Trust had a performance rating of one star.*

Group C	*This Primary Care Trust area provided healthcare for around 234,000 people and the overall population had increased by about 6% in the last ten years. The Primary Care Trust had a budget of some £197 million and had a two star rating.*
Group D	*This Primary Care Trust area provided healthcare for about 231,000 people and had a budget of £242 million. The area has one of the highest ratios of older residents and had a high area of deprivation, and is ranked one of the most deprived areas in the country. The Trust had a two star performance rating.*
Group E	*This Primary Care Trust area provided healthcare for about 243,000 people and had a budget of £178 million. The Trust had a one star performance rating.*
Group F	*This Primary Care Trust area provided healthcare for about 251,100 people and had a budget of £200 million. The Trust had a one star performance rating. The area is predominantly urban industrial, but with significant rural areas to the north and west. The area has some affluent areas but also areas of social deprivation.*
Group G	*This Primary Care Trust area provided healthcare for about 188,000 people and had a budget of £140 million. The Trust had a two star performance rating.*
Group H	*This Primary Care Trust area is one of the smallest in England. The Trust area serves an extensively rural area with a population of around 98,000 and had a budget of about £78 million. Tourism is important with some areas being popular holiday areas meaning the population can almost double during the summer months. The area is one of the most deprived areas of Kent and is part of a regeneration programme.*

A variety of sources were asked for assistance in the process of locating the PPI forum groups, including the Forum Support Organisations, contacts with Primary Care Trust personnel and ad hoc leads. Ultimately, the researcher identified that although forum membership was a public appointment, members had not given consent under the Data Protection Act (1998) for their names to be divulged, so this meant that the public and indeed the Commission itself could only gain access via the Forum Support Organisation, who in turn had to request member contact via the Chairperson. For the researcher, this meant that the Forum Support Organisations (FSO's) were the only direct route to the Forum membership and for this research was affected by an introduction to the Chairperson of each Forum.

Eight of the nine possible Kent PPI forum Chairs agreed to schedule time at a planned PPI meeting to enable further discussion on the study. The researcher attended and made research presentations on the proposed study at the meetings of each of these eight forum groups. The short presentations described the aim, objectives and importance of the research and allowed each forum group member the opportunity to meet, and ask questions about the research study. All eight of the interested PPI forum groups were willing to participate in this research.

4.4.2 Research Strategy and Plan - Stage 1 - Individual Level

a) Forum Member Questionnaire Survey

i) Design and Pilot

A ten-item questionnaire was used in the initial survey of all lay members of the eight Kent Primary Care PPI forums. (Appendix 1). Aimed at collecting self-completed data from members of the target population, that is, from the lay representatives of the patient forums, the questionnaire contained a mixture of closed and open-ended questions on the demographic background, past involvement and future expectations. No other appropriate tested surveys had been found. The justification for considering and ultimately choosing this research method was as follows: Firstly, that the initial information required in understanding the establishment of the forums was of a more personal nature, for example, age, *ethnicity, reasons for involvement and expectations.* Secondly, to elicit information that could be explored in greater depth with the respondents, when using the semi structured interview methodology.

Topics of interest were identified for inclusion in the questionnaire in relation to the aims of the study. The ideas and topics were discussed with the research supervisor and were commented on by other University personnel from the research field. Finally, the questionnaire survey was piloted amongst the Kent-wide Ambulance PPI forum group to ensure some validity of the document. Bowling (2002) commented that the validity of the data could depend on shared assumptions and understandings and it was important to check that the pilot group interpreted the questions in the same way as the researcher. Bias was considered in the development phase, not least because assumptions could have crept in because of the researchers experience in the subject area of patient and public involvement. The comments from the pilot group were valuable in finalising the questionnaire survey document.

The main points from the pilot feedback were the importance of keeping the questionnaire short, as it was felt this would aid the level of responses. The only further comment was about the order of the section asking respondents to indicate their ethnicity. The pilot group felt that ethnic groups should be listed alphabetically so as not to cause any unintentional offence to respondents. These comments were addressed and the questionnaire amended accordingly before distribution.

The questionnaire was simply worded and printed clearly, using some colour, which was visually easy to read and comprehend. The title of the study and clear instructions were given. A different format (language or Braille) of the questionnaire would have been used to assist the forum members to participate in the research, if this had been required.

ii) Sampling Strategy

A practical difficulty in conducting this research on PPI forums lay in identifying the PPI forum members themselves as the forum support organisation would not divulge that data unless advised by the forums groups direct. The names of the forum group members were also not published and the only point of contact was via the respective Forum Support Organisation, charged with supporting the forum members from an administrative standpoint. During this period, the total membership of the forum groups varied between 66-87 overall members (see page 193), although this data is not conclusive. Each PPI group was intended to have about 10 members, so a maximum cohort of 80 would have been a reasonable estimate. Forum members were also volunteers, participating for very limited hours per month and although many individuals gave much more of their time, continuity and participation were often sporadic.

The questionnaire surveys were distributed and completed between February and October 2005. All members of the eight PPI Forums received a consent form (Appendix 2) and formal information sheets detailing the research (Appendix 3) immediately following the formal presentation to each PPI forum. Packs were handed out to members attending the meetings at which the research was presented. In addition, research packs for all non-present forum members were left for internal distribution. This judgement on distribution was partially based on the difficulties experienced in accessing the forums, mentioned previously. This also gave interested participants the potential and time to consider the questionnaire, ask questions on the overall study and decide on their full participation.

It is recognised that this form of data collection had the potential for a poor response rate, particularly when left or sent by post to potential respondents. Of the estimate of eighty members, this study achieved forty overall forum member respondents, who participated in either just the questionnaire or both questionnaire and interview (50% response). In general terms, a response rate in questionnaires and interviews of seventy-five per cent is generally accepted as very good (Bowling 2002), fifty per cent is therefore considered acceptable. Although non-response is a potential bias, the changing membership numbers within the forums is thought to have had an impact.

iii) Administration of the Questionnaire Survey

The completed questionnaires were returned, generally by pre-paid post, to the registered study address. All of the data was securely filed, and stored with access by the sole researcher only.

To ensure confidentiality of the data, no participant would be named specifically and only numbers or letters would be used within the thesis as identification for the researcher. This coded and anonymised data had limited access, which was again restricted to the researcher only. The data was kept as a computer record on a personal computer, with all reasonable precautions taken to protect the integrity of the data, with access by password only. The anonymised findings were discussed with the university supervisor only, during the completion of the thesis.

iv) Method of Analysis

The analysis of the questionnaire was undertaken by the researcher. The results from the questionnaire were recorded on the statistical package, SPSS, to allow thorough analysis. For the purposes of this research, it was an ideal package to use for coding and identifying data. It has the ability to present key facts and numbers in tabular form, which were particularly useful when profiling forum member details, or for rapid production of descriptive statistics where there was a range of answers.

With no experience of this software package, computer training was sourced from a recognised University service provider recommended by the package guidance. This training provided the researcher with the skills to input the data into a table, giving an easier and clearer format with which to analyse the information.

Some gathering together of the answers was necessary where they were repetitive or similar to keep the study manageable and meaningful. The questionnaire data was substantial enough to analyse and look for consistent themes or interesting differences. Issues that arose from analysis of questionnaire responses were taken forward in the next stage of interviewing.

b) Forum Member - Interviews

i) Design

Interviews are the most common technique used in social science research to gather data (Grbich 1999). The initial aim and justification for considering and ultimately using this method was to gain a deeper understanding of issues raised with the questionnaire and to allow identification of other issues of importance, for example, the forums in action and health issues addressed. The interviews were also completed between February and October 2005, following on from the distribution and completion of the questionnaire surveys.

Semi-structured interviews, by face to face and by telephone, were considered an appropriate means of increasing the amount of detailed information about PPI forums. No significant differences between the qualities of interview process – in terms of topic coverage, duration of interview etc, were noted, but following a schedule of interview questions (Appendix 4) assisted the process.

Face-to-face interviews were mostly carried out in the respondents own homes. The researcher was aware of the importance of establishing a good rapport with the respondent and there were no problematic distractions. Interviews were tape-recorded where respondent consent was given, and this assisted in giving an accurate verbal account. The researcher initially had concerns that the participants would be intimidated by the tape recorder, or would refuse to agree to the request. In practice, however, there were very few concerns over this and there was almost exclusive consent to record the data. The tape recorder was checked prior to each interview and new cassettes were used for each respondent.

The schedule of interview questions was developed and used, so as to begin with broad issues and then to deepen inquiry through more probing and specific questions. Probing can allow for further clarification, provide opportunities to explore sensitive issues and can enable the interviewer to clarify and explore inconsistencies (Hutchinson and Skodal Wilson 1992) and can be an invaluable tool for ensuring reliability of the data. The researcher was clear not to act as an impartial examiner but as a person entering into a dialogue, based on equality, but with some expertise on the subject. In considering interviews, it should not be assumed that interviewer and interviewee will fully understand one another and that both will share the same interpretation of meaning. However, the quality of the data collected may depend on the relationship established. The researcher sought, however, to establish a conversational style of interview, and to develop themes with interviewees as the interviews progressed. The researcher was also very conscious of active listening, an essential consideration as there are the implicit and explicit meanings within any interview process.

ii) Sampling Strategy

The sampling strategy matched that of the questionnaire survey. All of the PPI forum members who had completed a questionnaire survey were invited to conduct an interview. Of the forty forum member individuals who completed the questionnaire, twenty-seven agreed to this second stage.

Interviews were restricted to one and a half hours duration, recognising that the interviewing processes would be fatiguing for both researcher and interviewee and that it represents a significant cost to participants. All respondents had the choice of interview by telephone or face-to-face. Where the interview was face to face, respondents also chose the venue and timing, as appropriate. A translator or interpreter would have been used to assist the forum member to participate in the research, if required.

The initial forum presentations had allowed the participants to meet and ask questions of the researcher and to fully understand the aims of the study. To a degree, this made the interview situation more comfortable and less threatening for all parties. Building a relationship between the participant and the interviewer helps to promote quality of data. Part of building that relationship is to be able to understand and feel with the participant. It is necessary to communicate respect and to act honestly in accordance with the respondents own feelings (Bowling 2002). The researcher did have an understanding and an experience in the subject area, gained over many years, which enabled genuine empathy, without presenting any personal perspectives.

In addition, a total of 13 personnel from the related organisations were interviewed (described fully in 4.4.3 – organisational level).

iii) Administration of the Interviews

The interview tapes were all initialled and numbered following each interview and were stored with the interviewers separate notes. These notes were essentially a double-check, in case of any unintentional recording problems. The separate files were kept to ensure complete anonymity, (discussed further under Ethics in the Research Process, from page 174).

The researcher transcribed all the interviews personally and completed these as soon as possible following the interview process: each interview generated several hours of transcription. The transcriptions and the interviewers general notes were combined which gave a good range of data. As the transcripts were read and re-read, themes began to emerge from this data. The transcription of the interviews therefore assisted beginning the process of analysis by alerting certain themes of importance to this research.

All participants were sent a copy of the transcription and were invited to comment and agree. Any amendments were finalised and agreed before a second consent form was used seeking agreement to use the data in the research (Appendix 5), this form was also used for agreement of observations, from page 169).

iv) Method of Analysis

The researcher, using the experiences gained during the doctoral process, undertook the analysis. The final agreed interview transcripts were analysed using NUDIST Vivo 2, usually called NVIVO 2. The software was new to the researcher and training was sourced through the main distributor. Two separate training days were completed at both elementary and more advanced level due to the nature and quantity of the data from the interview sections.

The software provides a guide through many options and possibilities in qualitative data analysis, from creating and editing data, to its exploration, organisation, and linking, as well as searching modelling and theorising of an emerging analysis. The software made importing data direct from interview transcripts a relatively easy process, saving word files in rich text format and importing to NVIVO.

The software also made it possible to assign '*attributes*' to each document, for example, demographic data, which was useful in searching or more properly, limiting the searching, coding and retrieval from the files (Richards 2004). Data was coded into nodes and trees representing a data hierarchy. This coding developed during the process and became both logical and meaningful. The categories were indexed to data noting the frequency and contextual links.

4.4.3 Stage 2 - Organisational Level - Interviews, Documents and Observations

a) Interviews

i) Design

Further interview schedules were used to frame interviews with thirteen more key informants - relevant professionals from the Commission for Patient and Public Involvement in Health, the Forum Support Organisations and the Primary Care Trusts (Appendix 6-8). The main purpose of these interviews was to obtain information about the organisational setting for PPI forums, further data on the Forums, their relationships and activities, and to understand how the early development of the Forums was viewed.

ii) Sampling Strategy

Each organisation was contacted initially by telephone to identify the most appropriate contact. Letters were sent to request their participation, with an information sheet to give details on the research study (Appendix 9). Further contact was made to finalise the arrangements for meetings. The following access resulted:

- Two managers of the south-east regional organisation of the Commission for Patient and Public Involvement in Health organisation were interviewed. The main objective was to gain information on the policy, establishment and recruitment of the forum groups and the Forum Support Organisations
- Three managers of the Forum Support Organisations were interviewed, representing some of the views of the two Kent-wide support organisations,

primarily to give background on their respective organisations and to their organisational support role, in a similar way to the Commission

- Eight Primary Care Trust managers were identified, from each associated Trust. All of these professionals had Primary Care Trust responsibility for patient and public involvement, including working with the PPI forum groups. It was useful to understand the organisational perspectives but also to understand their working systems within patient and public involvement, particularly given the government agenda and importance to the subject. Finally, it was interesting to understand the working relationships with their respective forum group

In terms of the Trusts, permission had been sought from the Primary Care Trust Research Governance Manager for Kent, for agreement to approach the Primary Care staff and an honorary contract was agreed for the duration of the fieldwork (see Conducting Research within the NHS section, from page 177).

iii) Administration of the Interviews

A mixture of face to face and telephone interviewing techniques were used to collect data. The interviews were again tape-recorded; dependent on respondent consent and this gave a faithful account. The interviews were numbered following each interview to ensure anonymity but the researcher was mindful of confidentiality issues. Therefore, due to the relatively small numbers of respondents in this cohort, data was aggregated by organisation, primarily to ensure the confidentiality of the data so as not to give any indications specifically to the professional respondents involved.

Consent was obtained from all the participants prior to the interview and following the same process as the forum members, each professional was given a copy of their interview transcription for checking and further consent was obtained agreeing the content and giving permission to use in the research.

iv) Method of Analysis

All the interviews were transcribed, (by the researcher) as soon as possible following the interview process and this, with notes taken at the time of interview, gave considerable useful data. The range of key informants provided insights from quite different professional perspectives. In transcribing and reading the interview data, the researcher looked for patterns and repetitions, marking these across interviews, which gave an iterative picture of the messages raised.

b) Documents – Annual Reports

i) Design

As indicated previously other authors (Silverman 1993) have considered records as '*potential goldmines*' and valuable sources of data although should not be regarded as completely accurate representations (Bowling 2002). Data from all eight Kent Primary Care PPI forum annual reports was gathered year on year from 2003-2006. Documentation can provide a valuable source of data particularly when combined with other approaches (Grbich 1999). The PPI forums were known to have a requirement within their Regulations (2003) to produce annual reports. Although very selective and partial accounts of activity, these reports do give some indication to the networking and relationships of the forums, the type and extent of work covered by the voluntary forum group members and give indicators to the progress and development of the forums.

ii) Sampling

All of the forum group annual reports 2003-2006 were used, except one report, which was unobtainable. PPI forum members signed off the reports at the time and these were available by request from the Forum Support Organisation, but the reports were also then published on the Knowledge Management System within the Commission for Patient and Public Involvement in Health website.

iii) Administration of the Annual Reports

These reports and the data within them were in the public domain so there were no direct concerns about confidentiality of the data. However, there was equally no other way of checking the authenticity of this report information but it is accepted that this is an accurate record from the perspective of the PPI forum group. This data was collected following the completion of the interview processes.

iv) Method of Analysis

The document information was compiled into table formats detailing any important points and noting the relevant criteria on meetings, work plans and issues addressed. This was then highlighted, and information aggregated collectively to see if there were any key similarities or differences between the forum groups.

c) Observations

i) Design

Observational data was gathered from six PPI forum groups during May and September 2006. The researcher attended PPI forum group meetings following the completion of the questionnaire survey, interviewing processes and the ongoing document analysis. The choice of these dates, therefore, had no other prior significance.

Observational methods seek to understand interactions and meaning from the perspective of the insider (Bowling 2002). Observations of activities, actions, behaviours and interactions were seen as useful for this research to get a better sense of the way the forums operated in practice and to assess claims that had been made in interviews about forum practices. Wolcott (1981) compared methods of observations but clearly detailed that field notes are essential, with time taken to expand, elaborate and to reflect on them.

The main reason for the observational stage was the relevance to validating and triangulating the research data. However, it is acknowledged that the meetings were a '*snapshot*' of individual forum proceedings, but they gave the researcher a clearer indication of the structure and processes of the groups.

The PPI forum groups knew of the proposed attendance at the meetings, which were also open to the public as well. Some respondents had commented about the interactions and relationships between the members and the professionals, and therefore observations were considered a useful means of confirming the quality of the data collected. The setting was therefore natural and was useful in understanding and checking the experiences of the PPI forum group and understanding the dynamics with the organisations and the public.

ii) Sampling

Many of the forum groups were having difficulties with recruitment and retention and had problems at times in reaching a number able to proceed with public meetings. As reported previously in Chapter 3, the forums were not required to have a formal meeting quorum but major items of business did need a majority vote. However, few member attendees at meetings made operating procedures difficult. The observations were therefore dependent on the meeting taking place and resulted in six observational accounts over the five-month period in 2006.

It was recognised that some members of the forum groups had changed since the initial questionnaire and interviews or simply had not attended the forum meeting on that occasion. The observations were still considered of value on the basis that these were used primarily for checking and validation purposes.

iii) Administration of the Observations

Extensive notes were taken during the observational section and copies of the agenda and relevant meeting papers were distributed and used. These notes and researcher observations were again kept confidential and in keeping with the other research data. As indicated previously, a consent form was used for agreement to use data from observations (Appendix 5).

iv) Method of Analysis

The data was analysed using a similar aggregated format. The data was useful in verifying the working arrangements and types of issues addressed by the forums and gave some indication on member profiles. The data certainly assisted, and verified the professional and forum member comments when looking at the working relationships with respective Primary Care Trusts.

In summary, this section on data collection has set out the processes involved in collecting and analysing the data from the participating Kent PPI forum groups. The study focused on individual forum members, and on the forums groups themselves and a variety of linked methods were selected - questionnaire survey, interview, documentation and observation to provide a rich, multilayered picture.

The following table, (4.4), represents diagrammatically, the overall pattern and quantity of data collection by PPI forum group.

Table 4.4 Showing the overall pattern and quantity of data available by forum group

PPI Forum	Questionnaire Surveys	Interviews	Annual Reports 03-06	Observations
Group A	3	2	3	1
Group B	4	4	3	1
Group C	7	4	3	-
Group D	4	3	3	1
Group E	4	3	3	1
Group F	6	3	3	1
Group G	7	3	2	-
Group H	5	5	3	1
TOTALS	40	27	23	6

4.5 Data Analysis and Theory Building

Hammersley and Atkinson (1995) note that:

'The analysis of data is not a distinct stage of the research. In many ways, it begins in the pre-fieldwork phase, in the formulation and clarification of research problems and continues through to the process of writing reports, articles and books' (p.205).

Scientific enquiry was built on a philosophical framework of deductive logic with the concept of inductive inference being formalised in the seventeenth century (Bowling 2002). A variety of philosophers have contested these views and the scientific method consists of a system of rules and processes on which research is based and against which it can be evaluated. Research has to be completed rigorously and systematically with the researcher carrying out and collecting data that is valid, reliable and unbiased, and finally presenting clear conclusions based on the data (Russell and Wilson 1992). However, it is important to understand that research standpoints and individual values could influence the analytical processes and research outcomes and to realise that the final research account is only an incremental process, findings gradually developed, clarified and substantiated.

The most common recognised approaches to qualitative analysis assume that there will be large amounts of data and that this data needs sorting into categories and labelling (coding) appropriately. As highlighted previously, this researcher had a package of data in various forms: questionnaire surveys, interviews, written documentation and observations. In common with other researchers, it took time to consider how best to analyse it.

As the sole researcher, this research study presented a number of challenges: for example, how to manage a set of data and its variables: how to keep track of the analysis: and how to do the data justice. With the questionnaire survey, interview transcripts and documents mounting up, the quantity of data required computer software to assist the analysis process. All of the research data was sorted into categories using the two different computer software packages. However, one question was constant, '*What is really being said*?' After several sessions and readings of the data, themes were identified and the development of the research process can be summarised as a table of theory development (table 4.5 below) following the guidance of Eisenhardt (1989).

4.5 Table of Theory Development for Case Study Research– Eisenhardt (1989, p.533)

Step	**Activity**	**Reason**
Start	Define research questions	Focus on study
Cases	Theoretical sampling	Used to extend theory
Research Instruments	Multiple data methods	Triangulation evidence
Fieldwork	Data collection and analysis	Familiarity with data
Shaping hypotheses	Replication of data	Sharpens theory
Literature	Comparison	Building internal validity
Closure	Theoretical saturation	End process

Theory provides the basis for explanation and making sense of the research findings. The processes of researching and theorising are in a constant relationship but are described from different perspectives (Russell and Wilson 1992). Two popular distinctions about the development of theory are described from the deductive and inductive positions. Deductive and inductive reasoning constitutes an important component of scientific reasoning and knowledge. With deductive reasoning, the researcher starts with general ideas or a concept of social life and develops a theory and testable hypotheses from it. The hypotheses are then tested by gathering and analysing data (Bowling 2002). In contrast, inductive reasoning begins with the observation and builds up ideas, more general statements and testable hypotheses from them for further testing based on further observations. This reasoning is grounded in data from the real world. In this research, the initial challenge was to frame '*common-sense*' presumptions about PPI forums in terms of a theoretically significant question – about the democratic and functional contributions of the forums. Moreover, from this frame, more specific questions and assertions could be established, for example, concerning the contribution to community representation made by the PPI forum members.

4.6 Ethics in the Research Process

Research ethics refers to the moral principles guiding research, from its inception through to completion and publication of the results. Carrying out research in a professional and ethical manner involves balancing a number of different principles, which often lie in tension with each other. The researcher considered their personal role in this, and acknowledges the importance of maintaining high ethical standards in social science research. Social science is a broad and varied subject but one that often involves human beings and therefore it was important to follow the six key principles of ethical research as specified by the Economic and Social Research Council (ESRC) framework (2006). Broadly these are:

- research integrity and quality assured
- all subjects fully informed
- confidentiality and anonymity respected
- voluntary participation
- avoid harm to participants
- independence of research – conflicts of interest to be explicit

The framework is an attempt to reflect, disseminate and standardise current good practice in the context of a rapidly changing environment and to ensure that the public remain confident in United Kingdom social science. It is also important to have a set of standards and guidelines that are relevant specifically to social science rather than drawing on those developed primarily for more clinical-based research.

The researcher considered the RESPECT code of practice for socio-economic research, which is a voluntary code of practice covering the conduct of socio-economic research in Europe. Many of the principles are similar to the ESRC framework but the RESPECT code emphasised, and recognised the importance of individual researchers to make the often difficult professional decisions and that it is also the responsibility of their employers, professional associates or funders to support them in making their decisions.

Patient and public involvement is both an ethical and political issue and raises interlinking questions about both the topic and the process. Patton (1990) advised that ethics is a *'pattern of knowing that focuses on matters of obligation or what ought to be done'*. Knowledge within this domain requires understanding of ethical theories, the condition of society, conflict between different value systems and ethical principles. The researcher fully considered these points:

- choosing a topic that was of interest and had values. There could have been a reaction to participants, and the data had to be acceptable and valid although research free from values is rare
- informed consent – negotiated with individuals participating in the study, respecting anonymity and keeping all matters confidential. The researcher had respect for the high levels of personal trust placed throughout the research. Polit and Hungler (1993) said that when humans are used as research participants great care must be exercised in *'ensuring that the rights of those humans are protected'*
- the importance of stating and restating the confidential nature of the data and ensuring participants had full information about the aims of the study
- checking and agreeing the data for accuracy and content with all participants
- dissemination of the findings – thoughts of how this could be achieved giving the future axing of the forum groups and the possibility of groups losing their membership

The dimensions of research ethics range from basic protection of participants rights to active endeavours to improve their lives. Accountability, and the relationship between the researcher and the researched is a key issue. At the '*rights*' end of the scale, it is generally accepted that it is unethical to harm anyone in the course of carrying out research (Grbich 1999). Deception regarding the purpose of the research; creating embarrassment, emotional turmoil or other forms of distress; harm brought to people through studying them without their knowledge; violating promises of confidentiality or falsifying or presenting results out of context, are all deemed '*unethical*' practices.

It is also important to remember that the voluntary sector often works in contexts often characterised by inequality, disadvantage, disaffection and conflict and not surprisingly, issues around values, power and participation are more prominent than in some other areas of social enquiry (Scott et al 2000).

As described in the next section, National Health Service ethical committees now run to a defined format, which ensures that all potential participants receive an explanatory letter or information sheet, detailing the aim of the study, the people involved and a full description of the possible outcomes. There also has to be a clear statement, a promise of anonymity and confidentiality and an indication of how this will be maintained. These ethical processes are fully detailed in the next section.

4.6.1 Conducting Research within the NHS

For this research study, the process involved completing two levels of ethical committee approval, one being independent peer review at Keele University and the other via the NHS Research Ethics committee process. The former process consisted of two internal and one external reviewer assessing the study on its importance and relevance, its strengths and weaknesses on design and methodology and the quality of the proposed analysis plus the capacity and expertise of the researcher. Once this process is completed fully the documentation and approval letter are submitted with the NHS application.

At the time of ethical submission, the NHS processes had just changed to a new system of standard operating procedure (March 2004). The process consisted of completing a large detailed on-line application form. This form is used by all NHS Research Ethics Committees (REC's), no matter what sort of research is planned or what REC is involved. The form was divided into three parts, these consisted of parts A and B containing questions on the overall project which are for review by the main REC. Part C of the form contains questions specific to an individual research site and is intended for further assessment by the relevant local REC. Following the submission a Part D, was also added to the research application process. REC applications can only accept submissions prepared using the electronic system. Finally, NHS research and development management approval is required from each organisation where the study will take place. There was also a separate checklist for manual submission to the research ethics office. All of the paperwork to be used in terms of questionnaire survey, interview schedules, information sheets and letters to participants had to be included.

Approval and written approval was granted following the researchers attendance at the ethics committee meeting. Each year the NHS ethics committee required annual updates on progress and to be kept informed on any changes to design or on any changes to key elements of the research. This researcher also needed an honorary contract to complete the research within the Primary Care Trust setting as the main employment was working for independent GP partners.

The means of obtaining this award were via the overall Kent Primary Care Trust Research Manager, who monitored the research thesis on behalf of all the Primary Care Trusts, using the Department of Health's Research Governance Framework for Health and Social Care

(2001). The criteria used in this framework were considered current best practice and all research and development projects conducted within or in conjunction with Trusts were conducted in this manner.

The honorary contract consisted of an agreement between the principal researcher and the named Primary Care Trusts in Kent. The duration of the contract was for a period of two years from 1/1/2005 to 31/12/2006. The purpose and status of the agreement was to enable the completion of the research within the Trust premises and with Trust employees and to ensure compliance with the above mentioned governance framework (March 2001), and all individual Trust policies and procedures. In terms of researcher obligations, these consisted of conducting the research in accordance with the governance framework principles, following the Trust's ethical rules, particularly in relation to its duty of care for patients, health and safety, confidentiality of Trust data, occupational health, equal opportunities, security arrangements and intellectual property.

As the sole researcher, it was important to give advice on the relevant skills and expertise obtained to undertake the research. This part of the process was completed by application form, a research protocol and an interview with the Primary Care Trust Research Manager. The final requirement was the completion of a Criminal Records Bureau check and that appropriate medical defence or professional indemnity insurance cover was secured.

In all, the peer review ethical process and applications took about fifteen months. The research study was scrutinized rigorously but overall fairly, and certainly the process increased the researcher's personal knowledge and understanding of the requirements at this level of study. However, this has made the researcher consider just how many research projects are left uncompleted with applicants being unprepared or unwilling to tackle this amount of paperwork on top of the demands of the research itself.

4.6.2 Reflective Diary

Grbich (1999) pointed to the importance of reflection as a research method as it sheds light on the topic either explicitly or implicitly. Huberman and Miles (1994) also highlight *'a reflexive stance'*, which involves keeping regular ongoing documentation, including successive versions of coding and dead ends.

The following points were important when considering why a reflective diary would be useful throughout the research study and were adapted in part from Cryer (1996):

- to show a high degree of self discipline
- to demonstrate development in thinking
- to provide ideas for the future direction of the research
- as an aid to reflection on record keeping and data
- to help improve time management

A reflective diary was completed during the course of this research process to keep reasoning transparent and an open mind and critical approach to the research (Silverman 2005). Hammersley and Atkinson (1983) commented that the construction of such notes *'forces one to question what they know, how such knowledge has been acquired, the degree of certainty of such knowledge and what further lines of inquiry are implied'* (p.165).

Elce (1992) also notes three concepts of reflection:

- when we become aware how we feel about the ways we are observing, understanding, thinking, acting or of our habits
- when we access how effective are our perceptions and thoughts, actions and habits of doing things
- when we become aware and make value judgements about our perceptions, thoughts, actions and habits in terms of like/dislike, positive/negative etc

The reflective diary was a useful tool and noticeably assisted in recounting any thoughts following meetings, interviews and observations around this research. This researcher kept an account of the event and any behaviour in terms of feelings, thoughts and ideas. Usually, there was an expectation or prior sense of a meeting although when reflecting afterwards these often actually transpired to be different from the expectation. After all the interviews, the researcher was able to pick out themes and usually was able to pick out something illuminating or interesting from the meeting, albeit a learning point or interview technique.

The researcher always had a sense of whether the interview had been a '*good*' interview and quickly realised the importance to the process of interviewing. The quality and the substance of the data had some dependence on the relationship established with the respondent, the capacity to listen, the enthusiasm and interest, the compassion and the necessity to stay focussed all the time.

Any conclusions drawn from the experiences were recorded, which assisted matters during this research study. Reflection has assisted in recognising the strengths and limitations of this research, which has proved to be a complete learning experience, which has contributed to personal development and will assist with future research projects.

4.6.3 Reliability and Validity

Assessing the quality of research is a difficult task, not least since there are many threats to the reliability and validity of an investigation. These are known as biases and errors in the conceptualisation of the research idea, the design or the sampling and process of the study, which can in turn lead to deviations from the true value (Patton 1990, Bowling 2002). Bias was considered at all stages of this research study. As examples of this:

- the researcher did not use their subject experience to make assumptions about PPI forums
- all PPI forum members had a calculable chance of participation
- no one value was taken as necessarily unimportant
- the design and data collection techniques were reviewed and were considered appropriate.

Issues of reliability and validity are often major criticisms of qualitative research. The argument hinges on the view that the research is subjective and therefore unreliable and invalid. This is often based on the assumption that the researcher's presence influences the behaviour of participants, thus altering the data. Another criticism is that participants may lie or withhold information to the researcher, therefore distorting or causing bias to the data. Although perhaps getting everything right is an unworkable aim, researchers should, as Wolcott (1990a) suggested, try to '*not get it all wrong*'.

Miles and Huberman (1994) take the view that qualitative studies take part in a real social world, which can have real consequences in people's lives; that there is a reasonable view of '*what happened*' in any particular situation; and that those who give accounts of it can do so well or poorly and should not consider their work unjudgable. In other words, that shared standards are worth striving for (Howe and Eisenhart 1990, Williams 1986). All of these authors encouraged thinking practically about how to reflect on the question of '*how good is this piece of work*', looking at matters in the form of asking questions. In terms of objectivity, are the study methods described explicitly and in detail and are there a complete picture of the Primary Care PPI Forums?

Some case study researchers (Yin 1994, de Vaus 2001), advocate a research approach that they see as value free; they aim to remain detached and to remove or minimise the impact and influence of their own position - the underlying concern is with demonstrating rigour and the delivery of credible conclusions, whereas others insist on an explicit declaration of their values. Research values would not just inform the research process; they also determine the extent to which a researcher takes a critical perspective, by this meaning locating the words and behaviours of individuals or groups within a broader societal framework. In considering this in the context of the research, a fundamental problem when working with volunteers and voluntary groups is to decide how far and in what ways their own values should shape their work. In practice, however, it is important to realise that it may not be possible to translate research values into practice; contexts and contingencies will ultimately shape choice.

In terms of reliability, are the research questions clear and consistent over time, and is there effective '*quality control*' of the study. The researcher considered the issue of the research questions and the personal role and status within the study and felt that this had been stable throughout the research. All research matters have been done with reasonable care and consideration at all times. All the data was collected across a range of setting times with appropriate respondents, as suggested by the research questions and the study did correspond with what was known about PPI forums. Peer review had been in place at all times and consistently considered the connectedness to theory, although these changed or developed over time as the research and personal understanding developed.

In checking the internal validity of the study, the researcher endeavoured to consider each stage of the findings. The researcher was initially aware of the importance of the questionnaire survey, and the need for the questions to be relevant, reasonable, unambiguous and clear but relevant for use with all participants. The questionnaire survey was piloted and amended using the comments from an unconnected PPI forum group. Similar processes were completed for the information sheets, consent forms and interview schedules via peer review and ethics committee scrutiny. The interview and observation methods were designed to address internal validity by checking/triangulating and deepening the findings of the survey process and then ultimately feeding back these findings to members of the PPI forum groups.

The external validity of the findings was addressed by assessing the evidence arising in this study against existing knowledge and against other studies in the composition of patient and public involvement forums and through explication of the limits placed on generalization of the findings (Mays and Pope 1996). The findings from this research within Kent cannot expect to be capable of generalisation across all groups regionally or nationally.

The final point in considering this research is to reflect on what the study will do for the participants, meaning the researcher and the researched plus any other interested person. All researchers have a duty to ensure that the evidence, both positive and negative, produced by well-designed research studies is disseminated. Effective dissemination requires that the research reports and papers be presented clearly and honestly. However, even with well-structured dissemination, there are still no guarantees that professional practice will change (Bowling 2002). The findings from this research should certainly raise some insight into the establishment and operation of Primary Care PPI forums, which in turn, could lead to further patient and public involvement developments and considerations, both locally and nationally.

4.7 Conclusions

This chapter has set out the design for the research into the establishment and operation of the Primary Care patient and public involvement forum groups, and the processes involved in collecting and analysing the data from the participating Kent groups. The study focused on individual forum members and on the forums themselves, and a variety of linked methods were selected - questionnaire survey, interview, documentation and observation to provide a rich, multilayered picture. The key focus for the research was to understand the composition of the PPI forums, their expectations and relationships, their capacity to represent their communities and the future policy implications.

Two levels of analysis were identified in this study. First, the individual forum member and second, the forums aggregated as a whole. The individual level was important in establishing and understanding the character of the forums and identifying the type of volunteer that made up these groups. Data was collected via a questionnaire survey and an interview process to give more depth of understanding. The second (organisational) level of analysis examined the operation of the forums and gave indications to the forums in action. Here, data from the member interview process was supplemented by interviews with related organisational professionals, annual report documentation and observations from forum group meetings.

Involvement in this level of research study has had an enormous impact on the researcher's personal and professional attitude and behaviour. It took some time to realise the full basis of the Doctoral concept, and the necessity to personally organise and consistently re-organise. There were numerous plans, and as stated previously a reflective diary was completed and used. The progress was not always easy but it aided the iterative nature of thinking. This form of constructive re-visiting actually provided real learning, as occasionally there was the thought that an area was complete, only to feel the necessity to revisit, rethink and rewrite. The study was at times frustrating, complicated and difficult, particularly as the researcher continued to work full-time for much of the study but important as strengths were found which had clearly developed as part of this research training.

This researcher was often acutely aware of her ethical position due to the importance of maintaining high ethical standards in social science research, in this case the importance of following the six key principles of ethical research as specified by the Economic and Social Research Council (ESRC) framework (2006).

This researcher learnt new technology in terms of NVIVO2 and SPSS computer programmes so that the data could be coded accurately and emerging themes could be identified and developed.

The process of writing up the thesis was different and strange, particularly as the researcher was used to writing and finishing managerial reports within a work environment, was used to covering the details quickly, getting to the conclusion and keeping recording to a minimum. Progress at times seemed slow and it was uncomfortable to write leaving gaps and unfinished processes along the way. It is now seen that the writing is a reflection of a rigorous interplay between personal thinking and the materials that form the data: the writing process is considered as much a part of learning as all the other steps in the research. In conclusion, the personal learning and development throughout this Doctoral research has had clear positive implications in the development and analysis of the study data.

The following chapter looks at the study results at the first (individual) level and in particular identifies the background and experiences of forum members to give some understanding of the character, establishment and early operation of the groups.

CHAPTER 5

RESULTS -THE ESTABLISHMENT AND CONSTITUTION OF THE FORUMS

5.1 – Introduction

This chapter sets out findings from the research about the composition of the Patient and Public Involvement Forums. Specifically, it reports the number, age and gender of the volunteers who formed the body of the PPI forums over the study period. It also gives details about the reasons for becoming involved, about the process and experience of recruitment to the Forums, about the volunteer training offered and undertaken, and about member's understanding of their role as *'representatives of their communities'*. These findings are intended to give some information and indicators about PPI forum establishment and to add to what has, so far, been limited independent research into the character and composition of the PPI forums. This chapter focuses on the data collected about the composition of the Forums: questions raised by the data are flagged and these are returned to in Chapter 7, Discussion and Conclusions.

As described in Chapters 2 and 3, all participating PPI forum groups were formed in a manner specified in legislation and shared certain rules and statutory powers. The rules governing these forums came from the following key documents: Statutory Instruments (2003) No 2123, The Patients' Forums (Membership and Procedure) which sets out the membership procedure regulations and Statutory Instrument (2003) No 2124, The Patients' Forums (Functions) Regulations, which listed the functions and regulations for PPI forums. Regulation No 2123 was very clear about the expected or intended membership. For reference, these were a minimum of seven group members appointed for a term of office of between 1-4 years. That the majority of members should live in the Primary Care Trust area and should include a representative of other voluntary or carer organisations, a former or current patient, and a representative from the local hospital Trust forum.

The Commission for Patient and Public Involvement in Health had responsibility, in law, for the establishment of the Forums and for the recruitment of volunteers to Forum membership, following these regulations. The rules that are most relevant to PPI formation in Kent are also explained in Chapter 3, but where appropriate, there are reminders in this chapter to assess whether practice has followed the expectations of PPI forums, as embodied in the formal rules and Regulations.

Outside of the statutory powers, the Commission for Patient and Public Involvement in Health gave guidance and recommendations in terms of good practice only. In 2003, each forum member received membership guidance from the Commission in the form of a reference guide (CPPIH 2003). The purpose of this guidance was to provide an overview of the PPI forum member role, and indicate the support available to members. This was followed by a further forum member handbook in 2004 (CPPIH), the second handbook was shorter and more specific about the rules and powers of PPI forums and was produced following a process of member consultation.

For reference, the main stages of the fieldwork were completed between February and October 2005. During this time, the groups were administered by a local Forum Support Organisation, recruited by the Commission for Patient and Public Involvement in Health through a tendering process, as a local not for profit organisation. The intention was for Forum Support Organisations to support and service at least two patient and public involvement forums on a geographical rather than specialist basis using their knowledge of well-developed local networks and their experience of working within their local communities. At the time of this fieldwork, two Forum Support Organisations covered all eight of the Primary Care PPI forum groups that are the subject of this research.

The tables and narrative within this section present aggregated data from the member questionnaire survey on PPI forum composition. There is also added data from forum member interviews plus relevant subject interview data from participants of related organisations, such as the Commission for Patient and Public Involvement in Health, Forum Support Organisations and Primary Care Trusts. Some data is also used from the patient and public involvement forum group annual reports, from the years 2003-2006, to give more thorough and detailed information for reasons of comparison.

Neither the forum groups, the forum members nor organisational personnel are specifically named in order to safeguard respondents. As part of the ethical processes, the researcher advised that all respondents would be covered by strict rules on confidentiality. As a part of this, respondents were informed that they would remain anonymous. To aid understanding, however, the following table (5.1) highlights the prefixes to direct quotations or referencing:

Table 5.1 Referencing of Quotations in Chapter 5 and 6

Type	**Group/Organisation**	**Reference/Prefix**
Forum Members	By anonymous number	1-40
Commission for Patient and Public Involvement in Health personnel	By prefix and number	C1-2
Forum Support Organisation personnel	By prefix and number	FSO1-3
Primary Care Trust personnel	By prefix and number	P1-8

5.2 Understanding the Profile of the Forum Members

5.2.1 Numbers

It was intended that the PPI forums would actually comprise of ten to fifteen group members (C1). However, following the consultation process, this number was amended to ten members, with a minimum of seven (CPPIH 2004). Despite setting a statutory minimum (CPPIH 2003), the regulations did allow a forum to continue even if its membership temporarily dropped below seven, although vacancies had to be filled as soon as possible. For reference, statutory instrument 2123 (NHS 2003) stated that the majority of members were intended to be patients/users that lived in the same locality as the Trust. Membership was also to include community/voluntary group members who supported the interests of others, the whole aimed at representing patients and local communities in the planning, management and scrutiny of local health services. If the forum was near to an NHS hospital then a member of the hospital forum also had to be included as an extra member.

Table 5.2 (next page) indicates that the participating forum groups varied both in the overall membership size achieved and in their membership over time. These figures only provide a numerical annual summary of the membership at the time, (2005), and do not attempt to trace the many changes to membership that happened within each group. The south-east office of the Commission advised that they had difficulties in recruiting a minimum of seven members for each Forum by the start date of December 2003 (C1). The Commission for Patient and Public Involvement in Health also advised that an overall membership of ten per group was considered very good (C1), meaning that the forum members that participated in this study (40) made up approximately 50% of the total available cohort.

Table 5.2 - Summary of the Kent Forum group member numbers 2003-06 (from forum group annual reports)

Forum Group	2003-04	2004-05	2005-06
Group A	3-5 members	9 members	5-7 members
Group B	11-13 members	9 members	9 members
Group C	9 members	12 members	9 members
Group D	11 members	12 members	6 members
Group E	10 members	10 members	10 members
Group F	10 members	10 members	7 members
Group G	10 members	No report available	8 members
Group H	10 members	10-15 members	10 members

Although membership numbers in some groups, like B, C, E and H seem quite constant, the aggregate numbers hide what was a regular turnover of members. The individual forum annual reports give some information regarding this fluctuating membership during the period 2003-2006, but were not always specific about the changes and retention difficulties. Groups including A and D in particular, had constant recruitment and retention difficulties and had to amalgamate at times with a neighbouring group. Many found very early on that it was unrealistic for them to attempt a detailed work plan or to support a full programme of activities due to these changing numbers.

"We really need about 15 members with at least 10 being really active" (24)

"To be effective we need a minimum of ten members, in terms of completing all the tasks, remembering that not everyone can attend all meetings or participate in ongoing forum activities" (1)

"If we are ever to get anything done, we need more members" (5)

"10 members is an absolute minimum" (17) – (The minimum requirement of ten members was raised in a similar way by a further six members)

Reasons for the turnover of members include decisions to resign early in a membership period (where members may have decided that the concept or the level of commitment was not for them). However, 30% of resignations were for health related reasons: this may not be surprising as some people were involved due to a health related experience, positive or negative, and also, as we will now see, the majority of members were from older age groups.

5.2.2 Gender and Age

The gender and age characteristics of the men and women who emerged to play this public role provide an important further basis for this collective profile of the Kent Primary Care PPI forum membership. Ongoing West Kent Primary Care Trust annual reports (2006/07) reported that the population remained an almost 50/50 split of men and women, with the majority aged between 35-59 years of age. The greatest increase in population over the coming years is expected to be in people over the age of 65 and with this trend, there will be changes in the local population health needs, predominantly focussing on diseases in older people (West Kent PCT 2007).

Of the total forty PPI forum member respondents to the questionnaire survey, twenty were men and twenty women, therefore giving an even aggregated 50% spread. This gender balance over time was found in at least six of the forum groups although the other groups varied only slightly between male and female members. The south-east office of the Commission confirmed that:

"The gender split regionally is fine around 50/50, forum by forum" (C1)

Table 5.3 (below) shows that the vast majority of the respondents in the questionnaire survey were over 46 years (39 respondents/97.5%) with 34 respondents (85%) being 56 years and over. Other studies of volunteers (VDS 1995, Forster 1997) record a similar pattern. Both these studies indicated that age was seen as a positive advantage and an asset, due to life experiences and the ability to weigh up decisions.

Table 5.3 Summary of Data from Survey - Question 2 - Age Group

	Ages	18-25	26-35	36-45	46-55	56-65	Over 65
Group A	M	-	-	-	-	1	-
	F	-	-	-	-	1	1
Group B	M	-	-	-	-	-	1
	F	-	-	-	-	1	2
Group C	M	-	-	-	1	3	-
	F	-	-	-	-	1	2
Group D	M	-	-	-	-	1	1
	F	-	-	-	-	1	1
Group E	M	-	-	-	-	-	1
	F	-	-	-	-	2	1
Group F	M	-	-	-	1	-	2
	F	-	-	-	1	-	2
Group G	M	-	-	-	-	1	2
	F	-	-	1	-	-	1
Group H	M	-	-	-	1	-	4
	F	-	-	-	1	1	-
Totals		-	-	1	5	13	21

There is no doubt that the age profile in this sample of Forum members was heavily skewed to the over 50s:

"The age range is very definitely 50 plus" (29)

"The majority are over 65 years of age, with one or two slightly younger" (30)

"We are all more elderly members" (37)

"We are all around the same age group (50-60s) with no younger people" (36)

"We are mostly middle income, middle class and in the retirement bracket" (16)

The Commission for Patient and Public Involvement in Health regional office also confirmed (C1) that Forum member age ranges within the southeast region were very similar to those found in this research.

"We have attracted a disproportionately high number of older people, the majority being in the 56-64 or over 65 groups" (C1).

5.2.3 Ethnicity

As previously mentioned in Chapter 4.4, Kent is a very diverse county, given its spread and mixture of rural, town and coastal areas. It also has a changing population given the port of Dover, the Channel Tunnel link and being within close proximity to major airports. It also has coastal tourist areas that become heavily populated during the summer months.

In terms of this research study, and using the 2001 census for the Kent area, the ethnic mix of the forum groups was proportionate and matched the demographics of the region (96.9% white); however, this did not necessarily mean this translated down exactly to the current local community structure (www.statistics.gov.uk/census2001). It is also clear that since the last census, the population trends are changing given the documented transient population and all areas of Kent, similar to most counties, have ethnic minority communities (West Kent PCT 2007).

However, the demographics make clear that the majority of ethnic minority groups live in the North Kent areas and in addition, some of these are areas of relative deprivation. These communities and to review and monitor local health services, therefore representing much more in political terms. Lowndes (2001) in looking at trends of participation in local authorities said, "*It may be unrealistic to seek balance or representativeness within groups*". However, that it was important to use a variety of participation methods and appropriate incentives to engage those who would not ordinarily take part. This situation may always cause a dilemma in terms of, on the one hand, building the competence of those involved and, on the other hand, continuously widening the process to include new individuals. There are certainly no quick and easy answers as initiatives need to develop over time, together with the education, confidence and trust of any traditionally excluded groups.

In summary, what is apparent is that the membership process to the Kent forums was not specifically targeted to achieve compositional representativeness within each individual group but from a county perspective, this was achieved given the local area demographics. The data on membership numbers and data from the member interviews reflect that recruitment and retention was an ongoing difficulty outside of attempting to achieve a truly representative sample. Recruitment is discussed further in the next results section, 5.3.2 and the debate around representing the community is continued in Chapter 5.4, page 214.

5.3 Member Involvement, Recruitment and Training

5.3.1 Reasons for Involvement

The majority of people involved in this research had multiple reasons for becoming involved (table 5.5 next page).

Table 5.5 Summary of Data from Survey - Question 4 – Reasons for Involvement

		Past experience in Health/ Social Care	Interest and want to help in community	Previous background as volunteer	Personal development or future employment	Time available	Other reasons
	Persons						
Group A	3	2	2	2		1	1
Group B	4	3	4	4	2	2	
Group C	7	6	5	5	4	4	1
Group D	4	3	2	1	1	3	1
Group E	4	3	3	2	1	4	
Group F	6	6	5	6	2	3	3
Group G	5	5	3	2	3	5	1
Group H	7	4	3	4	3	4	2
TOTALS	40	32	27	26	16	26	9

A number of respondents (32) had a past experience or interest in health care previously, 27 had an interest in the community and 26 respondents had been a volunteer before. In general, this past volunteering commitment was linked to health, some respondents being from Community Health Council backgrounds (14).

"I wanted to make a contribution after being a member on various groups. I come from a background of volunteering and felt I could do something useful here" (28)

Previous volunteering commitments (table 5.6 next page) were often in the form of either an NHS volunteer, GP patient group volunteer but by far the largest group of ex-health related volunteers, as previously indicated, came from former Community Health Council members (16 of the 40 respondents). Some respondents had been volunteers in all of the three categories given.

Table 5.6 Summary of Data from Survey - Question 7 – Were members former CHC, GP Patient Group or NHS Volunteers?

		CHC	GP Patient Group	NHS Volunteer	No previous involvement
	Persons				
Group A	3	2	2	1	1
Group B	4	1	1	1	3
Group C	7	4	1	3	2
Group D	4			1	3
Group E	4	2			2
Group F	6	6			
Group G	5			1	4
Group H	7	1		2	4
TOTALS	**40**	**16**	**4**	**9**	**19**

Twenty-six of the respondents interviewed indicated one of the main reasons for joining the forum was that they had time available. This also went some way to explaining the lack of working people in forums, although some forums had tried to accommodate working people by holding forum meetings at different times of the day. A number of respondents had retired or semi retired from work linked in some way to health or social care and the PPI forums maintained this interest and these individuals were also used to working around health issues and/or with patients and the public. Some members interviewed (20) expressed the opinion that employed people could only participate if they or their employers could be supported financially, as is the case for jurors, and that this would be the only way of engaging a wider public to give time to their communities (discussed further from page 207). It is clear, however, from the previous table that almost half (19) had no previous involvement in specific health related groups.

5.3.2 Recruitment

The membership and recruitment of the PPI forum groups was the responsibility of the Commission for Patient and Public involvement in Health. Although the organisational structure was devolved to regional offices by the Commission, one would justifiably assume that recruitment and advertising would follow the same pattern throughout each forum group. From the information collected, this was not necessarily the case, and there were some local variations.

Table 5.7 – Summary of Data from Survey - Question 4 – How did you first hear about PPI Forums?

		Advert	Press	TV	Leaflet	Website	Recommend	Other CHC
Group A	M	-	-	-	-	-	-	1
	F	-	1	1	-	-	-	-
Group B	M	-	1	-	-	-	-	-
	F	1	-	-	-	-	1	1
Group C	M	-	-	-	-	-	2	2
	F	1	-	-	-	-	-	2
Group D	M	-	1	-	1	-	-	-
	F	2	-	-	-	-	-	-
Group E	M	-	-	-	-	-	-	1
	F	-	-	-	-	-	2	1
Group F	M	-	-	-	1	-	-	2
	F	-	1	-	-	-	-	2
Group G	M	1	-	-	-	-	1	1
	F	-	-	-	-	-	2	-
Group H	M	-	1	-	-	-	3	1
	F	1	-	-	-	-	1	-
Totals		**6**	**5**	**1**	**2**	**-**	**12**	**14**

Table 5.7 (above), shows that the majority of forum members first heard about the PPI forums through personal recommendation. This usually meant recommendation via a current forum member, employee of the Forum Support Organisation or alternatively via the former Community Health Council network. Primary Care Trust professionals also recommended people to Forum groups, often people that were currently part of the Primary

Care Trusts own patient group. Some (6) of the Primary Care Trusts had their own patient groups, which fed into or worked alongside the PPI forum groups.

Former members of Community Health Councils (CHCs) were accepted as forum members. Comments were extremely variable as to whether ex-CHC members were advantageous to PPI forum groups. Some respondents (18) commented that forums with ex-CHC people gave the impression of strength, as members were much more aware of National Health Service terminology, the usage of abbreviations and acronyms, and because they had relevant past experience and useful contacts. Of these, the majority view was that there was a real need to evolve and restructure and that there had been huge disparity regionally and nationally in terms of how the former CHC's managed themselves.

Secondly, regional media was used to recruit perspective forum members initially. However, it seemed unreasonable to expect the south eastern regional office in Guildford, Surrey to generate great enthusiasm for recruitment in Kent. The profile of the PPI forums was therefore not very high unless you worked in or around health. From the literature (CPPIH 2004/05), it is clear that advertising campaigns were often kept centralised, or were generated via the Forum Support Organisations (FSO's), who equally had a low and unadvertised profile. Some Kent PPI groups, for example groups D and H, jointly ran local newspaper advertisements to increase membership, but these were sporadic and did not achieve high response rates. Other recruitment campaigns were tried via voluntary organisations or by promotions using local public areas, but it is unclear from the annual reports as to the extent or frequency of these. In addition, only one of the two Forum Support Organisations had its own website.

In summary, prospective volunteers would probably only know about the PPI forums if they were particularly sensitised to the opportunities of influencing and contributing to health service governance. For example, if they had had some positive or negative experience in health and felt impelled to join a group to address this situation or they had experience as a volunteer linked to a hospital, patient group or former Community Health Council group. More than a quarter of the forty forum members interviewed in this research were concerned about personal health agendas and commented that some group members had experienced an incident (often negative) which had prompted their forum participation.

"Most of our group, about 80%, have had some first hand experience of an incident (generally negative) that has made them volunteer to come forward"(15)

"Often the issues that members bring are driven by personal experience, so there is a personal agenda in most cases" (17)

"Many members have joined the forum because of particular issues that have motivated them to join and some have been members of pressure groups based around an illness" (1)

"Some members of the group have their own axes to grind" (6)

The statutory Forum Regulations (2003) set a maximum period of forum membership of four years. This meant potentially that members would have to leave, possibly at a time when they were becoming more proficient and familiar with not only their role but with the complicated workings and terminology of the National Health Service.

The Commission for Patient and Public Involvement in Health acknowledged that recruitment was an ongoing difficulty (C1, C2) and confirmed that the recruitment process was confusing for new members. They also suggested that the two main reasons for the poor ongoing membership numbers were the low profile of the groups and the time commitment.

"It is always difficult to find people who are representative and who are willing to give the time and the commitment to do the work" (C2)

The Commission felt that many people also resigned as the commitment in time was far greater than first envisaged, although acknowledged this could have been made clearer at interview bearing in mind that members are recruited on the basis of volunteering for two or three hours per week. A high majority of the respondents interviewed (26) indicated that it was not unusual to complete far more than the recognised hours, some identifying as much as ten to twenty weekly hours, including communications and the volume of paperwork that was distributed regularly. Almost all the Kent forum groups in this study have struggled with the recruitment and retention of members. In turn, this has often led to a limiting of the work schedule, (identified in Chapter 6). Time commitment is detailed more fully in Chapter 6, as it is more directly related to forum activity and capability.

The Commission could provide allowances for members, such as travel but also compensation for loss of remunerative time (Patient Forum Regulations, 2003). However, these allowances were left to the Commission for Patient and Public Involvement in Health to determine and, whilst members were reimbursed for their mileage expenses, loss of work time did not appear to be available for reimbursement in Kent. No respondents raised this aspect of the payment for time legislation, which may indeed have given more opportunities for working people to be involved.

Behind the low profile lay an issue of resources. The Commission's budget allocations meant that there was a lack of resource to support and sustain each forum (C2). During the 2005/06 financial year, the Commission's budget allocation could not sustain more than ten members per forum (C1) and so it was fortunate that Forum membership did not reach the original planned target of fifteen per group. The regional Commission office operated with only twenty staff members covering ninety-three South Eastern forums, but this also extended to the lack of budget for advertising and the necessity to group and limit interviewing processes. One of the Commission professionals (C1) commented that:

> *"It is absolutely fair to say that the resources have been incredibly stretched and we could have done with a lot more resources to provide good service performance"*

Staff skills are particularly critical in supporting and encouraging new people who want to get involved. Many staff appointed to work with the PPI Forums, particularly those contracted to provide staff support, were inexperienced with little knowledge of the NHS (C2). They were not therefore in a position to advise or support members and help them to contribute with confidence or expertise (see also Hogg 2007, who commented on these issues when looking at the requirements of both CHC and forum members).

Warwick (2007) and Baggott (2005) have also commented on the costs of the PPI forum system on the pressure placed on the Commission for Patient and Public Involvement in Health to recruit over 4,000 people in less than nine months. The Commission was concerned that recruitment of volunteers would always be problematic (C2), as it had been with Community Health Councils. The PPI forum role was demanding and, as noted in Chapter 3, could not rely so heavily on the energy and commitment of paid officers, as the Community Health Councils had been able to do (Klein and Lewis 1976, Moon 1995). Community Health Council members were either formally employed or nominated by voluntary organisations and although they were not regarded as representative in a strict sense, they did see themselves with a collective responsibility for all patients/consumers.

It was relatively common within Kent forums to have a number of ex-CHC members although Warwick (2007), in contrast, has indicated that few ex-CHC members served on forums in his area. About half of the PPI members interviewed (14) felt strongly that the Community Health Council had to change, but in general that this could have occurred without disbanding and re-starting PPI forums.

"I got into CHC's and from there it became a career" (23)

"I was disappointed to finish with the CHC and worked for them as long as possible" (24)

"There are a number of former CHC members and their interest is still relevant" (7)

Was then the system of member recruitment, application and selection justified? The Forums themselves had no choice in either their forum support organisation or the staff provided for them (Hogg 2007). Alternatively, might a return to the more traditional methods of nomination by civil servants and health bodies have produced the range of members, able to represent their communities? In either case, it would be futile to pretend that the answers could be found in individual social backgrounds and past involvement. However, and arguably, selection could produce different types of person and introduce elements of variety and experience, which may otherwise have been lacking. At least this would give some balance to the respective group's, as high numbers of volunteers with no experience in any one group would not necessarily assist progress, given the documented need to understand NHS systems, terminology and abbreviations.

Is there also a need to incentivise patient and public involvement in some way? Offering a realistic fee to people who have expressed an interest on the basis that they are recruited randomly to represent the socio-demographic characteristics of their respective communities might have broadened the pool of applicants. There is often a dilemma in encouraging and motivating people to participate and building on the competencies of those willing to be involved and on the other hand continually widening the process to include new participants (Lowndes et al 2001, Lowndes and Wilson 2001).

The PPI forum model could, for example, follow a citizen jury concept. Participants attending citizen juries are usually paid a daily or weekly rate and other studies, like Lenaghan et al (1996) have shown good levels of attendance and reasonable success in these situations. Citizen juries are an attempt to meaningfully involve members of the public in decisions, which affect them and their communities. Lenaghan's study concerned a pilot citizen jury, where professional recruiters used a demographic breakdown of an area to recruit sixteen members of the public. Over a four-day period, the jury were presented with information to help them reach a number of decisions concerning priorities for purchasing health care, the idea being to enrich rather than replace the pre-existing decision-making processes. Each juror received payment, importantly no juror dropped out, and attendance was good throughout this time. The majority (23) of the forum member respondents interviewed in this study, however, voiced concern at receiving payments, as in practice this can be difficult as any form of paid employment could actually affect and cause deductions of other kinds of benefits. Many respondents also advised of the value placed personally on volunteering, as most members had been touched in some way by the health service, although this could ultimately be a negative as well as a positive experience.

The interview experience of the Kent respondents was certainly variable and did not follow a more standardised interviewing format. There was an expectation of a professional approach, but twenty-four of the forum member respondents interviewed made negative comments about the recruitment process.

> *"There was a long delay from applying to being interviewed – the process was very torturous and unnecessarily so. The interview when it finally came was very superficial and almost laughable"(1)*

The same respondents indicated that often interviews were conducted by telephone, although the expectation had been for a more formalised process. Warwick (2007) described his own rushed experience of recruitment following a ten-minute telephone conversation. Many respondents found this method of telephone interviewing strange, given the necessity of this role, to work with and in the community at large.

> *"The process of recruitment was an absolute outrage and when it finally happened, (following delays on the day) it was clear that the interview team did not know what they were interviewing for. I felt that if this had any bearing on the organisation I was about to commit to then I would really rather not, it was a farce" (29)*

Fifteen Forum members interviewed were concerned that the people conducting the interviews had no idea as to what was involved in representing patients in health issues and simply repeated the questions to which each member had already responded on the application form.

There were also long delays following the interviews to receiving a final answer as to whether the application was successful and members often had to chase the Commission for this. The following comments reflected a common theme:

"I am sure many people refused to join at that point as they thought that the organisation was unprofessional" (30)

"It seemed the Commission did not have the capability to process perspective members quickly" (9)

Baggott (2005) and Gaze (2004) reported that recruitment to the forums had been problematic from the start with many groups struggling to reach minimum numbers. The fourteen respondents that commented advised that the overall appointment process was rushed and guidance on other important issues such as remuneration, conflicts of interest and police checks seemed to evolve rather than giving the impression of being thought of in advance, which is similarly confirmed by Warwick (2007).

So what can be concluded from these clear recruitment failures?
First, there was a necessity to follow good practice for all public appointments, like the principles recommended by the Office of the Commissioner of Public Appointments (OCPA), as detailed in Chapter 3. The OCPA guidance on appointments states that there should be clarity on the competencies and experience required for any group or panel, that there should be a job description and person specification to define the tasks and the qualities sought and that consumer representatives should be treated on an equal footing to other members of an organisation. The fundamental point raised is the necessity to address what you want the consumer representative for, but there was no clear evidence of a detailed person specification.

The Commission for Patient and Public Involvement in Health acknowledged that recruitment of the minimum of seven members on each Forum within the timescale dictated by the government and Department of Health had been a real difficulty (C1). The

Commission also acknowledged that many of these failures were linked to budgets and under-resourcing, particularly in the number of Commission staff, all of which had effects on the establishment of the PPI forums. As detailed previously and in Chapter 3, other authors have indicated that the whole PPI system was not generously funded (Baggott 2005). A research study completed by ACHCEW (2002b) calculated that £53 million would be required to provide the *'fit for purpose'* level of staffing and this compared with only £30 million actually spent in 2003/04. There is always the dilemma of budgets and funding and any new organisation will encounter significant cost pressures, particularly in the first year. Perhaps budgets could have been used more effectively if there had not been the pressure to establish the PPI forums so quickly, following the abolition of Community Health Councils and other authors have raised this concern (Baggott 2005, Warwick 2007).

5.3.3 Appointment of Chairs

Another area that created strong feelings was the appointment and the role of the Chairperson. The membership guidance (CPPIH 2004) stated that a Forum could appoint a chair, but this was a recommendation and was not therefore compulsory. Each PPI forum could determine whether it would appoint a chair (and deputy chairs) and for how long these members could hold these respective positions. The chairs, therefore, had no specified role, but the guidance (CPPIH 2004) recommended that the chair or deputy chair should always chair meetings in public. All of the eight Kent forums within this study had appointed a chairperson.

Once the demise of the Commission for Patient and Public Involvement in Health was announced and accepted in 2004, the future appointment of Chairs was the subject of further debate and discussion. The proposition that another outside body would appoint a Chair with no pre-existing knowledge or relationship with forum members was not seen as the right way forward. Overall, eighteen of the respondents interviewed felt that there would be serious resistance to external appointments and that the Chair needed to be chosen and appointed by the forum members themselves, as a person they knew and felt they could work with.

"If the Chair is appointed by a governing body, without forum support, then this would be seen as being run by the NHS and we would no longer be independent" (16)

"The group will want to appoint someone they know and have experience of working with; to some extent they understand their strengths and weaknesses. The forums also feel it is like having an outsider appointed by an outsider. They perceive it as imposing a person on them by someone they perceive as not understanding how forums work. There is a lot of resentment to that" (17)

"I think if Chairs are appointed then it will probably be the death of the forums. I think you have to earn your worth of being a Chair and the forum group needs to be responsible for this" (28)

Appointment (and potentially dismissal) by another outside public body raised a basic question about Forum independence (see further discussion in Chapter 6). However, five forum members and six of the professional (PCT) responses saw good reason for a central appointments process for Chairs of Forums, for example by a government department. The role was seen as pivotal and there was a need for PPI forums to be seen to conduct themselves professionally and appropriately, particularly if they were to have any political leverage.

"The recruitment of the Chair is vital and I am quite supportive of the fact that this should be done by the Appointments Commission or similar body in the future" (PE)

"I would be happy for Chairs to be appointed by the government in the future so that hopefully we would not have members appointed with personal issues to be resolved" (38)

"The only way this could be successfully reformed is for the Appointments Commission to invite a forum to nominate candidates and then for the Commission to vet them. It would then give the Commission the opportunity to explain and advise if they disagreed with our nomination" (5)

5.3.4 Exclusion Criteria

The Forum Statutory Instrument Regulations (NHS 2003) listed criteria for the appointment of forum members, but there were also some criteria that could exclude appointment. The most interesting in terms of this study is that employees, members or officers of the NHS or any organisation providing health services for the NHS in the forum's area would not be considered for appointment. All five respondents from the Commission and Forum Support Organisations accepted that this seemed a reasonable exclusion in case of conflict of interest, bearing in mind that NHS staff had their own avenues for dealing with concerns and also had their own support mechanisms within their organisations. There was more debate about the exclusion of 16-18 year olds. Three of the organisational respondents felt that this age group should be encouraged, at least in a representational activity, bearing in mind the legal age threshold between adult and child.

"We are very short on younger people being members of the forum and I would like 16-18 year olds included for consistency" (F3)

In agreeing with Baggott (2005), the Forum situation was not helped by a clear failure of government to ensure that the various patient and public initiatives (as highlighted in Chapter 3), for example PALS and Foundation Trusts, did not conflict and undermine each other. In addition, why limit or set exclusion parameters from the outset, which conceivably can be misunderstood? Rather than have exclusion criteria, a robust recruitment procedure was necessary in which decisions could have been made regarding suitability for forum membership using a range of standard and recognised good practices.

5.3.5 Forum Member Training and Development

The majority of forum members (19) interviewed saw member training as important and in particular around development in the following areas: gaining a working knowledge of the sector, effectiveness within committees, identifying public concerns and developing skills to lobby and influence. Training that had actually been provided for and undertaken by the forum members was also identified. This ranged from eight or nine standard training packages of short day courses that dealt with competencies, including media training, monitoring of visits, chairing, and working as a forum. However, specific training was considered on an ad hoc basis, as each forum had an identified budget but it was not possible to establish the specific amounts allocated to each group or individual. Half (14) of the respondents interviewed had commented positively on forum member training, and advised that their training needs were being met.

"Training is continually provided and we are given a list of courses available. Members can choose and apply accordingly" (12)

"If we highlight something in particular then this would be covered for us" (28)

"We have had the opportunity to put our training needs forward" (29)

"It seems to be a good system of standard packages plus purpose built development" (4)

In the South East Commission regional summary 2004-05, a similar percentage, forty-four of the ninety-three South East forums had participated in some training and development. The one vitally important area that some respondents commented on was the need to understand health service terminology and abbreviations plus the general workings of the NHS and without this knowledge, members often struggled when joining PPI forum groups. This clearly had an impact when working directly with NHS organisations. Some members acknowledged the assistance of their Forum Support Organisation, other members were assisted by members who had previous experience from Community Health Councils, and others occasionally had assistance from their respective Primary Care Trust.

"I would appreciate knowledge of health service terminology and the workings of the NHS" (36)

"I realised that the forum was out of touch with the PCT and were not sure of structures or who to contact" (PA)

Whilst there was a degree of networking and development within the groups themselves, this was often limited to links with the local hospital PPI group, from which a co-opted member attended meetings to keep both sides updated on local health issues or shared work plans on a specific issue. Occasionally, neighbouring forum members had to combine due to limited membership, if numbers were consistently under the minimum seven. Kent chairs and deputy chairs met on a quarterly basis but there appeared to be little business collaboration, for example, on training, sharing good practice, or collaborative working and the groups appeared essentially to operate in isolation apart from their contact with their local Forum Support Organisation.

5.4 Representing the Community

The original draft reference guide for members of PPI forums (December 2003, version 6), published by the Commission for Patient and Public Involvement in Health, section 1.5 included the following as part of the role of PPI Forums:

- obtaining the views of patients about health services and making recommendations and reports to the NHS about these
- making recommendations on the range and day to day delivery of health services
- influencing the design of and access to NHS services
- providing advice and information on services to patients/public
- monitoring the effectiveness of local Patient Advice and Liaison Services (PALS)

The Primary Care Trust PPI forums had additional responsibilities:

- To promote, encourage and support PPI in health
- To represent patients and public views on matters affecting their health
- To provide advise to the NHS and other bodies on public involvement

PPI forums have therefore had the ability, in principle and following this guidance, to represent the interests of many of the most vulnerable people in society and within the local community.

Established to replace Community Health Councils (CHCs), PPI forums were formed to enable patients and the public to take part in decisions and for providers of health services to be more responsive in a form that would more clearly meet the government managerial agenda (Hogg 2007). The overall policy reforms in the health service, together with local government and other sectors have been oriented towards more active citizenship, overcoming social exclusion, and promoting participation at local levels within a framework of national standards (Stoker 2005). It is possible then to question the form Forums have taken. In particular, the narrow health focus of these PPI structures seems inconsistent (Banks 2001, Hogg 2007), given the identified range of measures to lower the boundaries between health and social care. Nevertheless, PPI forums are part of a State-sponsored encouragement for more direct democratic engagement in health and within this, the role of representation of a wider community remains a crucial plank. As the review of literature in Chapter 2 found, the representation of the patient, public or community is a complex, multi-faceted concept.

The following condensed table (5.8 below) shows, which group's within the community the PPI forum members felt they represented; members often stated that they represented more than one group.

Table 5.8 Summary of Data from Survey - Question 8 – Did forum members represent any particular group?

Forum Group		Ethnic	Health Related	Young Person	Older Person	Community	Disability	Other
	Persons		-	-	-	-	-	-
Group A	**3**	-	-	-	-	-	-	-
Group B	**4**	-	**1**	-	**1**	**2**	**1**	**1**
Group C	**7**	**3**	**3**	**1**	**1**	**3**	**2**	**4**
Group D	**4**	-	**2**	-	**1**	**1**	-	-
Group E	**4**	-	-	-	-	**1**	-	**1**
Group F	**6**	**1**	**2**	-	**2**	**1**	**2**	**1**
Group G	**5**	-	-	-	**1**	-	**2**	**1**
Group H	**7**	**1**	**2**	**2**	**2**	**1**	**1**	-
TOTALS	**40**	**5**	**10**	**3**	**8**	**9**	**8**	**8**

Fifteen of the twenty-seven respondents interviewed in this study indicated that they did represent patients and the public within their respective communities.

"To represent is giving voice to those who have difficulty in voicing their opinions as much as anything and from feedback I do represent"(22)

"That is the reason for being there, to represent" (37)

"I think that forum members are genuine in their beliefs that they are representing issues in the community" (17)

"I do represent the community on a broad range of issues" (35)

"To represent means I am there when people want me" (24)

"I have a great feeling for some groups in the community and some of the injustices in health that exist. I would like to feel that I am fighting somebody's corner" (28)

"I do represent the community in my forum work... I make sure I advise what is happening" (12)

Eleven forum member respondents felt, by contrast, that the forums did not or could not represent, on the basis that no body or organisation could truly represent, and that even elected Local Authorities did not achieve this. There was also discussion from these members on the diversity within the community and the problems of reaching all sections, meaning true representation was a virtual impossibility.

"I do not represent but I hope as a lay person in the community that I do always consider the local health needs" (36)

"We do not as yet have a means of feeding matters back to individual members of the public" (2)

None of the forum respondents gave specific examples of how they obtained local viewpoints, although many received information or concerns using their own community networks, which were variable in both numbers and range of health interest. This broad notion of community had different meaning and interpretations and these findings acknowledge, similarly with other authors like Jewkes and Murcott (Chapter 2, page 57), that it is impossible to reach final agreement on the meaning. For the patient and public involvement groups involved the term '*community*' identified a small local and more personal group or a friend or shopkeeper, on the basis that this was a manageable number given their time and voluntary capacity. Also, and as raised previously in this section and by other authors such as Hogg (2007), there was great value placed on the experiences of the individual user or patient rather than the larger community experience.

A number of forum respondents (20) indicated that the forum groups discussed community health issues before a decision was made to add to the work plan. What was not established was the number of people in the community that had raised the specific issue as one of importance. These same respondents were also aware that patients and the public needed to know and understand the actual PPI forum role to be able to fully interact. Banks (2001) has commented on confusing and complex structures, which often caused people to lose sight of the original purpose, and which actually deter the people it is seeking to involve.

"The difficulty is persuading the public that this process is there and to interact with it. If the public do not know we exist then we are only working on ideas we think are important" (17)

A small number of forum member respondents interviewed (3) commented on how much easier it was to address patient issues but public issues meant more about inequalities and deprivation or social and community structure, which were harder concepts for them as voluntary forum members to understand and to work with. In exploring these comments further, this was much more about accessing the wider public and obtaining a wider scope of views rather than those of individual patients and smaller networks, with concerns about excluding the views of perhaps the more marginalised, or those who are not organised within the community.

The topic health is quite transient and on reflection, one may only become involved if something personal had happened to you or someone close to you, this being either a positive or a negative experience. If your health is good then possibly you would get on with your life and the issues addressed by a patient and public involvement forum may not be pertinent. However, this means that forum members could be driven by personal experience, with a conceivable danger of personal agendas, and involvement for the wrong reasons.

Ten of the forum members interviewed were concerned about personal agendas. In fact, two of the forum respondents interviewed agreed that they had their own agendas and had clear views on what was also meant by involvement: that patient's should be fully '*informed*' about their condition, provided with relevant information and be involved with the practitioner/professional in the decision-making process, should they want to do so.

"The NHS system failed me and did not support me and I wanted to ensure that no carer was left without support in the future" (35)

"It is my view that I am putting forward together with views from the group I work with locally" (13)

Against the ideal of a properly representative body for each community, the recruitment to the forums was not apparently founded on a view of how the views of local people, particularly those who are not part of established networks, would be collected, or of the skills individuals needed to achieve active representation. Papers and toolkits on patient and public involvement (IHM 2000, Lambeth PCT 2005) have attempted to create strategies for developing engagement within the wider community. Indeed, the Commission made attempts in their forum training programme to create their own involvement and membership toolkit for use within the groups (CPPIH 2004/05). Only a few members (3) commented on the involvement training and these indicated that a culture of involvement was the ideal and the overall aim, but recognised that representing others was a skill that took time to develop. In addition, the reality was that despite the legal requirements, there was still some way to go to achieving a culture of openness and liaison with some NHS organisations. The Primary Care Trusts were asked about the importance of patient and public involvement and these results are identified in Chapter 6, page 233.

5.5 Conclusions

This chapter has reported findings about the composition of the participating Kent Primary Care PPI forum groups. It has been concerned to establish the profile of forum members, and whether, or in what senses, forum members felt they were able to represent their communities. Data was obtained using a questionnaire survey, plus interview data from both forum participants and participants from other related organisations. Forum group annual report data, 2003-06, was also used to give more thorough and detailed information for comparison purposes. While these results cannot be taken as a fully representative sample, nevertheless, the data have provided an emerging picture, one, which also assisted the design of other data collection stages.

The research found that forum group member numbers fluctuated, due to recruitment and retention difficulties and particularly so for two of the groups (A and D), who struggled to consistently meet the group minimum number of seven members. The numbers reported in this research, however, only reflect member numbers at the year-end as the annual reports did not always give clear indications to ongoing fluctuations. This pattern of changing and *'understrength'* membership of the forums was not just specific to this study. Hogg (2006) noted that it was a regular national occurrence, and a survey in the Health Service Journal (2004) found that many forums struggled to recruit members due to lack of resources. Commentators like Baggott (2005) and (Gaze 2004) have also commented on the recruitment and retention challenges.

Member's recruitment and selection for the PPI forum groups was the responsibility of the Commission for Patient and Public involvement in Health. The government had put pressure on the Commission to ensure minimum group numbers by 1st December 2003. It is likely that, as a consequence, the priority was more to achieve numbers, rather than to ensure that the people recruited were suitable and fully understood their membership role. Hogg (2006) and Warwick (2007) noted the governmental pressure and that commercial consulting teams were used to organise recruitment. Most did not have a background in the voluntary sector or an understanding of how volunteers would relate to their constituencies. Hogg (2006) also advised that to meet the deadline set by government (1 December 2003), Commission for Patient and Public Involvement in Health regional staff were cold calling potential recruits, giving the impression that anyone who applied was appointed. This study found that recruitment over the eight PPI forum groups did not follow a standard process. Very few respondents indicated that the interview process was well organised and formal, and the majority made negative comments, not only about their own experience, but also suggested that the process of recruitment and interviewing would have had a negative effect on membership numbers. Overall, it is likely that the changing and limited numbers of PPI forum members had an effect on the amount and extent of forum work programmes (see next chapter).

If PPI groups relied on volunteers, then what motivates people to join is an important factor. Chapter 2 reviewed a number of theories and models, which were discussed from self-interest to concerns about the community and the ongoing development of competencies and responsibilities. The Commission regional office (C1, C2) confirmed that the recruitment process was confusing for new members, and members confirmed there was very little briefing or follow-up on what being a member involved. Hogg (2007) commented that this induction was often compounded by meeting forum support organisations who knew little about patient and public involvement, or possibly the NHS or their local area.

The complex and massive PPI forum structure inevitably meant that there was great scope for misunderstandings and disputes, and ultimately this meant that the blame rested with the Commission. Like the public, the Commission had to communicate with PPI forums via the Forum Support Organisations, as members had not given consent under the Data Protection Act, for their names to be divulged, even though the membership was a public appointment. This was not an ideal start in terms of accountability or indeed for members to know or develop working relationships, particularly cross-forum.

Hogg (1999) and Salter (2003) have also identified the traditional difficulty that patients and the public have experienced in participating in health care decision making systems and Baggott et al (2005), in discussing consumer groups, described the importance of a professional approach, backed by clear evidence, where groups sought to influence the policy process. The majority of forum respondents interviewed in this research had clear views on the importance of the Chairperson to lead, advice, and bring cohesion, both within the current format and looking forward to the future.

In terms of the demographic composition or profile of members, the findings demonstrated an identical gender mix of twenty men and twenty women: indeed gender balance was found in all the participating PPI forum groups and ongoing membership changes did little to affect this. In terms of age range, the forum groups were very similar in that the vast majority of forum members were 56 years and over and nationally only ten per cent of members were under 45 (CPPIH 2003/04). Drawing predominantly from older age groups is not only common across PPI forums, but with volunteering in general. From the expected future population figures, there will continue to be a large cohort of potential older citizens who may be prepared to be involved in local issues. The ethnic mix, too, was similar across all the forums and insofar as representativeness in relation to the population is a useful criterion, matched the demographics of Kent; however, this did not always mean that each forum had even ethnic representativeness in these ratios.

Representativeness issues are an ongoing debate mentioned by other authors (Lowndes 2001b), and Community Health Councils were accused of similar failures (Cooper et al 2006). In terms of the nature of the forum member's appointments, representativeness would always be difficult to achieve and the nature and actions of the forum group could be seen as more important than its composition, but with an importance of finding ways to communicate with those termed as harder-to-reach in the local community (Health Service Committee 2007). PPI forums were originally required to represent the views of the public and to play an active role in decision-making. Representation is about a relationship between the representative and the represented, with the importance of seeking to balance different viewpoints. Half the number of member respondents interviewed made comments that they did represent patients and the public within their respective communities.

However, and as reviewed in Chapter 2, the real value of being a representative lies in the necessity to identify the patient/public need and to champion and move that interest and argument forward. No forum respondents, however, gave definite examples of how they obtained viewpoints and there is no evidence to show how patients or the public were represented from raising the issue internally within the group or externally to other organisations. There was also no evidence of feedback to the patients/public. Forum members used their personal but often limited contacts within their own communities, and these limitations were due, in part, to capacity given the voluntary nature of forums. The concept of community and the meaning individuals bring to the word, also reviewed in Chapter 2, was found to often mean a small contact group or set of individuals, rather than a larger and perhaps more expected geographical area.

In summary, the PPI forum member profile was similar to the regional profile and in general met the demographics of the area. The age ranges were also common to other PPI forum regional groups and linked to an increasing older age population identified by the Primary Care Trusts. Many of the forum respondents in this research came from a previous background in volunteering, and nationally the Commission had recruited one third of members who had volunteered before (CPPIH 2003/2004). Parry (1992) argued when discussing educative theories that individuals with a background in involvement were likely to pursue similar action as they developed confidence. Barnes (1997) argued that people develop and move from discussing their own experiences to reflecting how health services might benefit people who use them, and it is important to understand these motivations. Lowndes (2001), advised however, of the tendency to rely on a few committed individuals. There was little evidence found to support the fact that individual members were able to fully represent patients and the public, given both their often-limited community networks, the general lack of interaction with the professionals, and the lack of clear understanding or evidence of work programmes being informed by the experiences and opinions of the wider community. However, it should be remembered that PPI forums had poor membership recruitment and retention, little staff support and no separate budget. There were also questions about accountability and the legitimacy of members. Overall, PPI forums had little time to develop and get to grips with their roles. In spite of the difficulties, many dedicated PPI forum volunteers worked hard in terms of trying to make the new system work.

The thesis now moves on to consider data about the character of each forum group as a whole, in particular detailing the PPI forum process and activity, and identifies the relationships with the Primary Care Trust and Forum Support Organisations.

CHAPTER 6

RESULTS -THE PROCESS AND ACTIVITY OF THE FORUMS

6.1 Introduction

The detail in Chapter 5 surveyed the composition of the PPI forum groups and found that in terms of democratic representativeness of their local communities and of individual member understanding and expectations of representation, the establishment of PPI Forums left much to be desired. Although it was not possible to map retention of members exactly, it was also clear that as a consequence of the establishment process, particularly with regard to recruitment, PPI Forums experienced a distinct and unsettling '*turnover*' of members.

In this chapter, our attention turns to the establishment process of the Forums as an organisational force, looking specifically at how the Forums started to operate, to establish networks and their working relationships with the Primary Care Trusts and other related organisations.

As set out in Chapter 4, a variety of data collection methods were required for this second (organisational) focus for analysis. This chapter draws further on the interviews conducted with individual forum members and with representatives of the organisations directly involved. Data was also collected through observation of the Forum group meetings, which allowed a deeper sense of the character of each Forum and gave indicators to its relationship with its Forum Support Organisation and Primary Care Trust. Finally, data was drawn for the PPI Forum annual reports, which provide an account of Forum work plans and their activity.

The annual report material was in the public domain and therefore was important both as a validation of patient and public involvement forum practice and as clear examples of recent working practice. The reports themselves varied considerably in content, size and style, there were no photographs or colour and were not extensively detailed. The language style was not managerial but gave information on members, contacts, activities and work plans and each Forum Support Organisation (FSO) was responsible for ensuring production of the report.

The next section gives details of the forum groups networking and organisational relationships.

6.2 Networking and Relationships

This section identifies the networking contacts that the PPI Forums developed. These contacts are defined as networks or groups, including voluntary groups, that the PPI Forums made contact with from their establishment in 2003. These networks are purely seen an as indicator to PPI Forums developing and increasing their profile. Some forum groups had an expectation that other local networks could provide information and further contacts, as one means of advertising PPI Forum existence and encouraging engagement with their local population.

Relationships refer to the key organisational relationships with the statutory Primary Care Trusts, the Commission for Patient and Public Involvement in Health and the Forum Support Organisations.

Analysis from the annual reports shows that each group responded differently to the Forum role and some groups achieved a variable amount of networks and contacts quickly. In the absence of detailed annual report information, the researcher has used the quantity of contacts plus information on networks/contacts from the member interview process as indicators. One Forum Support Organisation (FSO) member (FSO3) commented that it was down to each forum to determine how they wanted to operate, however FSO's were intended to support and facilitate communication between Forums and other groups/networks within their local '*health community*' (CPPIH 2003). The drivers were supposed to be the local population, and finding out what they wanted the Forums to address (FSO3), therefore the start processes of contacting the local community often began with local networks/groups. The PPI forum groups were ultimately similar in contacting a range of groups or businesses common to all, for example, GP surgeries, schools, although each Kent area had slight variation.

From the annual reports 2003-06, networking information is summarised in Table 6.1 (next page), and confirms that little forum activity happened during the first year (2003-2004). The inaugural period, from 1st December 2003, was used more for establishing contacts rather than working on specific activities. It should be remembered, however, that for this financial year the detail relates to a period of less than three months actual activity as all eight forum groups similarly, had their respective inaugural meetings between January and March 2004. All but one of the groups used this first year to establish contact with the local Primary Care Trust and used this period for understanding their roles and responsibilities as forum members, the concept of Patient Forums, and the legal framework that they worked within, plus learning about local health services.

During this first year, meetings with Primary Care Trusts consisted of introductory meetings with senior staff and patient and public involvement leads to gain preliminary knowledge about local health services priorities and to have some understanding of proposed changes affecting the local community.

Table 6.1– Summary of Networking Contacts and Relationships 2003-2006 (Annual Report) data

Forum Group	2003-04	2004-05 - **Additional**	2005-06 - **Additional**
Group A	- PCT - Local voluntary groups - General Practices - Dentists, - Councils - Libraries	- NHS Direct, - PCT Board meetings - Breast/stroke care - Local school - Hospital radio - County Council PPI - Volunteer Bureau - Pharmacies	- Joint working with other PPI Group
Group B	- PCT & Patient Group - Cancer/stroke networks - Local voluntary groups - GP practices - Hospital 'friends' group	- Hospital strategy group - Cardiac Network - PALS - Parish Council - GP Practice Managers - PCT Board/clinical governance	- GP practice user group - City Council - OSC - Kent County show
Group C	- PCT - PALS/PPI leads - General Practice - Out of Hours service - Mental health leads	- PCT Trust Board - Choose & Book Group - Acute Trust PPI Group - Nurse Steering Group - Clinical Ethics Group - Councils	- Acute Trust Health & Social Care group - Equalities Group
Group D	- PCT - University of Kent - Research committee - Local voluntary groups - Mental health - General Practices	- Saga Holidays - PCT Patient Group - Health Promotion - Forum Chairs Group - PALS - Schools	- Choose & Book group - Expert patient group
Group E	- PCT & patient group - Community groups - Local medical committee - Mental health board, - Out of hours group - Cancer network - General Practices	- PCT Board - Social Services - OSC - Out of hours group - Reconfiguration group - Local cottage hospital - Chairs group	- Hospital group - Clinical Excellence group - Community Engagement Project
Group F	- PCT and PALS/PPI leads - PCT Board (observer) - Local OSC - GP practices - Doctors on call - Local hospital - Health partnership group - Hospital Trust PPI Group	- Leisure Club - Day centre - Pensioners Forum - Age Concern - Kent Messenger local newspaper - Councils - PPI Chairs meeting	- PCT Non Exec Directors
Group G	- Strategic health authority and PCT - Local community groups - General Practices	No report available	- Pharmacies - Practice based commissioning leads - Community care services
Group H	- PCT and PALS leads - Local media - PCT Trust Boards - Councils	- Local libraries and shopping centre (to meet public)	- Joint working with 2 other PPI forums - Local MP - Local homeless charity - Adult Social services

From the reports, introductory letters were identified, which made contact with local voluntary groups and organisations. Questionnaires were also used with the aim of obtaining information about other local organisations' involvement in health. Some members also used established personal contacts with local organisations.

In addition, all forum groups attended welcome days provided by the Commission and attended by representatives of the Forum Support Organisation. These initial sessions were targeted at team building and introducing the role of PPI forums, the Commission and the Forum Support Organisations.

During the second, but first full year 2004-2005, the forums continued to expand their networks and most had established regular meetings with their Primary Care Trust. As might be expected forum group activity appeared to increase, although over half of the forums commented on the time needed to understand the subject fully. Members were also designated to sit on a number of health related groups to give a patient's perspective and various members took lead responsibility for specific work projects. This year culminated in the announcement that the Commission for Patient and Public Involvement in Health would be abolished (CPPIH 2004).

In 2005-06, the emphases were still on developing activity and networking, and some local contacts were established, although it is unclear how these developed over time. The new problem for the Forums was of course the uncertainties regarding their future and this clearly had an impact on the retention of existing members and ultimately the workload. This was also coupled with health issues arising from the reconfiguration and restructuring of the NHS, which meant that NHS organisations were experiencing a testing time.

There were key organisational relationships around each PPI forum. The following narrative structures three sets of relationships: the Forums with their respective Forum Support Organisations (FSO); the Primary Care Trust with their local FSO; and the Forums with their Primary Care Trusts.

6.2.1 Forum – FSO Relations

As indicated in Chapter 3, the role of the Forum Support Organisation (FSO) was a key component in the overall structure as these local not-for-profit organisations were recruited to draw on their knowledge and experience of working within local communities. The scope of work of each FSO fell into three broad areas:

- To contribute to knowledge and information management enabling Forums to establish networks
- To provide training and development opportunities for members
- To meet the Forums' administrative requirements

FSO personnel (FSO3) made it clear that the role of the FSO was to provide support and guidance. The Commissions' scope of work (CPPIH 2003) blueprint stated that FSO's should not lead or influence, but a further FSO respondent (FSO2) indicated that a balance had to be struck, although certainly not leading the Forum agenda. This respondent indicated the Commission had been wary as there were tensions involved around leadership and helping people to go in the direction they wanted to go. There were no obvious signs that the FSO's were influencing the agendas, but from the observational data one FSO was either chairing or answering questions, in the absence of the Chair or deputy chair or where groups struggled to reach minimum numbers.

Forum members (27) interviewed had commented in a mixed fashion about the role of their FSO indicating that some tensions existed:

"I think we are very lucky and receive very good support from our FSO. The administration and research is invaluable" (2)

"I think they manage matters as best they can and they cope reasonably well" (15)

"The FSO needs to co-ordinate itself more and seems a bit unprofessional at times" (9)

There were also six specific comments on FSO accessibility and it should be remembered that each of the two Forum Support Organisations worked differently, one more locality based (with co-ordinators working from home and one permanent office) and the other providing a centralised one-office service. The FSO scope of work (CPPIH 2003) is not specific about premises, other than to stipulate that FSO's had to work from readily accessible community-based local premises. Both organisations were not known extensively to the general public and were not promoted locally, other than via the health service or forum member channels.

6.2.2 Primary Care Trust – FSO Relations

From the interview data, there were indicators that the Primary Care Trusts equally had variable working relationships with each respective Forum Support Organisation. Four PCT professionals indicated that they had joint meetings or regular contact with their FSO's. Two of the Primary Care Trusts advised that the majority of the contact with the members was actually via the Forum Support Organisation, rather than direct contact with forum members. The final two Primary Care Trusts indicated some difficulties with effective working.

"We do have contact and the office (FSO) ensures that all the members get the required information" (PE)

"More so with the FSO directly and we have a good relationship with them" (PH)

"I think it necessary to have some sort of support organisation but I am not sure how effective things are in the current format" (PA)

"I think we now have some sort of understanding but it has been a difficult road to establish ways of working" (PI)

Two respondents from the south-east regional office of the Commission for Patient and Public Involvement in Health were clear that the Kent Primary Care Trusts (PCTs) worked in different ways, similar to the regional picture, and this was a major factor in the development of relationships with both FSO's and Forums.

"In terms of the region we have Primary Care Trusts that are open and work constructively and positively with the forums and others who just seem less aware of the value of the relationship or are skeptical about doing patient and public involvement" (C1)

"For any organisation to have good patient and public involvement, it has to be culturally within the organisation and has to be led from the top. Where you find an organisation which is not that inclusive and one where the team at the top is not that interested then it will struggle everywhere" (C2)

Forum Support Organisations were contracted based on their experience of working within the local community rather than any defined experience of working with NHS organisations. Therefore, there was a conceivable gap here is their ability to assist forum members in their communications within the NHS. The two Forum Support Organisations also indicated in interviews that the Primary Care Trusts worked differently:

"PCT performance has changed over time and much depends on the commitment of their Board to PPI" (F3)

"The relationship that we and the forums have with their respective PCTs has been quite different. Some PCTs have a common understanding of PPI, others have struggled to deliver" (F1)

Therefore, against the knowledge that legislation was in place (Section 11), meaning a duty for Primary Care Trusts (PCTs) to consult with their communities, there was evidence that PCTs not only worked differently but that they were not were in a position to respond to the requirements.

Five of the eight Primary Care Trusts interviewed had some nominated personnel working on patient and public involvement, although these were often roles linked to PALS or complaints. All commented that patient and public involvement was seen as being within every professional's role and of the need to cascade the principles throughout their organisation. The other three Trust personnel advised that patient and public involvement was something that had to '*be done to others' (PB),* and *'PPI had not been invested in and was not seen as important compared with other PCT priorities' (PA).*

6.2.3 Forum – Primary Care Trust Relations

The forum members themselves had very mixed experiences and views of the working relationship with their respective Primary Care Trust. Seventeen members of the twenty seven interviewed felt that progress had been made and that there was co-operation on various issues. Five others felt the commitment to patient and public involvement was superficial, and it was only pursued given the need politically to demonstrate co-operation. These members argued that the prevailing professional culture of the NHS remained strong and that there was little real evidence to show that anything was changing.

"I do not think any PCT is on board with PPI" (34)

"I find it sad that there is suspicion around PPI" (7)

"We have had a plethora of requests to attend PCT committees and this makes me think that we are simply allowing them to tick a box" (17)

And on the other hand,

"I think they (PCT) are genuinely trying to look at PPI. If we prove we are a good organisation (Forum) that is representing patients, we can build trust and we will have a good working relationship with our PCT" (23)

"They are keen to engage us and do try to co-operate with us" (6)

Five of the Primary Care Trusts indicated having their own PCT (internal) patient group or collection of lay people that could be asked to participate should queries arise or where public opinion was needed. They sought to rationalise the range of lay member forums in a variety of ways: One Primary Care Trust professionals commented:

"I see our patient, carer and public involvement steering group as part of our own internal checks and balances. I see the patient forums standing outside the PCT but looking in as a critical friend. I think our PPI Forum is doing ok" (PF)

Another said,

"I cannot really see an effective role for the forum members. I think that they feel they should be investigating things and tend to give only negative comments and it is very rare to get positive comments" (PG)

This caused discussion about the effectiveness of the PPI forums and the duplication of effort and work. The eight Primary Care Trust professionals had mixed views on the PPI forum groups, their roles and their approach:

"The forum members themselves feel a little directionless and are not clear exactly what their role is, which is confusing in trying to get an overall picture of how to support them" (PA)

"I have the impression that the quality of the people involved is possibly better than the CHC system, however, it makes me wonder why collectively they are not making more of a show" (PC)

"Perhaps we have exchanged the CHC for the PPI forum" (PD)

All of the above quotes indicate that the role of the PPI forums was not clear to the Primary Care Trusts. PPI Forums were set up differently from Community Health Councils who depended largely on paid officers as well as a voluntary or co-opted network, rather than the member-led PPI Forum model, with a contracted not for profit organisations supporting administratively.

There were some noted differences in relationships between the PPI forum groups and their Primary Care Trusts, which became more apparent when observing some of the forum group meetings, (also see Appendix 10). Of the six groups observed, one group (Group F) had a notably good relationship with their Primary Care Trust. Equally, one forum group had a notably difficult relationship (Group H). These differences substantiated some comments identified from the interview processes, from both forum member respondents and Primary Care Trust personnel plus researcher observational notes and reflective diary. Any observational evidence from the meetings used all the usual parameters including body language and tone, which was notably different when comparing and contrasting each event. The other observed relationships were more difficult to assess, as meetings did not run to plan due to limited numbers or Primary Care personnel not being in attendance.

In summary, the working relationships between the forums and their respective Primary Care Trust organisations were certainly variable. Some organisations had dedicated personnel and gave evidence to suggest understanding the importance of patient and public involvement and the necessity to cascade the concepts throughout the organisation.

The next section details the development trajectory of forum activities in the first three years.

6.3 Examining the Activities of the Forum Groups

6.3.1 The Development of Forum Activities

It is important to make some assessment of the PPI forum group activities and priorities. The level of forum activities are documented in the groups corresponding annual reports and are adapted in table 6.2 (next page).

Table 6.2 indicates that during the first year (2003-04), six of the eight forum groups similarly attempted to raise their profile and inform patients and the public about the role of the Forums. This awareness raising included giving presentations to other local groups and having promotional stands in public places, plus some advertising in the local press.

Table 6.2 - Adapted Summary from PPI Forum Annual Reports indicating main Forum activities 2003-2006

Forum Group	2003-04	2004-05	2005-06
Group A	- GMS GP Contract - Out of hours	- Out of Hours survey - GP contract/visits - ICAS/complaints info - Presentations on PPIF - Breast care review - Pharmacy review - Presentations/profile	- Out of Hours survey – jointly with other forum - Availability of dentists (joint working as above) - Choose/Book meeting - Presentations to groups/profile - Reconfiguration meeting
Group B	- Local service delivery plans – mapping area - Raising profile of PPIF - Working with PCT - Out of Hours	- Fact finding visits - GP appointments and GMS contract - Meeting patients/profile - Response to consultation on Intermediate Care - Comments to PCT policies/strategies	- Community Hospital visits, report to PCT Review Out of Hours -Intermediate Care - Access to GP services - Nutrition in hospitals - Clinic closures - Comment on PCT performance
Group C	- GP surgery survey - Raising profile of PPIF - Mental health service closures	- GMS contract - Improve publicity and PPI representation - Equality development - Improve PCT knowledge - Work on MS guidelines	- Inter forum work on mental health - Cultural awareness - Learning Disabilities - Monitor GP closures - Raise PPI group profile - Attend/represent public at core PCT meetings
Group D	- Information on services, mapping area - Raising profile and working with PCT	- Availability of dentists - GP appointments - GMS contract - Advanced Access - Mental health review - PPI engagement/profile	- Men's Health - Out of hours - Urology review
Group E	- Review local services/profile - Working with Trusts - Out of hours	- Mental health and older people - GP contract - Hospital hygiene - Women's & Children's issues - Community/profile	- Hospital bed closures - PCT reconfiguration - Disabled access -Drug/alcohol and obesity - Homeless/asylum seekers etc
Group F	- Men's Health (GP practices) - Children's/Adult services - GP contract - Local hospital admissions	- Learning from complaints/PALS - Special Needs children - Engaging with local people/profile - Improving PCT/NHS knowledge - GMS contract issues	- Working with other forums/profile - Mixed sex wards - Privacy & dignity - Out of hours - Pharmacy applications - Treatment centres
Group G	- Working with PCT and PALS - Roles and responsibilities/profile	- Monitor PCT via PALS reports/complaints - Reconfiguration - Respond to public issues/profile - GP contract	- 0870 telephone lines - Diabetes services - 28 day prescriptions - Men's Health - Representing at PCT meetings
Group H	- Information on local health services/PCT - Contact local community/profile - Patient information	- Access, Choose & Book - Treatment Centre - Mental Health services - Engagement/profile	- Access in Primary Care - Cleanliness in hospitals - Sexual Health - Intermediate care - Imaging equipment

As described previously, the forum groups also had meetings with their Primary Care Trusts. These meetings were aimed at understanding the roles, services and issues faced by the Primary Care Trust and to gain an insight into the local area health profile and local service delivery plans. They were also designed to discuss and agree a draft programme of activities for the second year and finally to improve their knowledge of local health issues, areas of deprivation, key targets and the resources available.

During the second year, 2004 – 2005, all but one forum (Group A) expanded or maintained their membership (as described previously), although these figures are not specific about the ongoing retention difficulties. All eight participating forums had similarly indicated more engagement with the community and continually attempted to increase the profile of the forums. This involvement continued to range from presentations or information stands, advertising in local press or occasional press releases on their existence and their work. Although there is evidence to suggest engagement was attempted, data from member interviews show that six of the participating PPI forum groups had difficulties in generating much interest from the wider community. These groups had ongoing poor attendance at forum group open meetings. These members and groups commented on the public apathy and lack of interest, but matters in health are perhaps only important if we or people we know are directly affected.

Only one of the forum groups (Group F) commented on good levels of attendance at meetings when interviewed. A large proportion of this forum group's membership had remained constant and the group appeared to have a good relationship with their Primary Care Trust, wanting to prove that they were a credible group. The Trust invited this forum to attend PCT Board meetings and attempted good working practice and communication.

"If we prove we are a good organisation (Forum) that is representing patients, we can build trust and we will have a good working relationship with our PCT" (23)

Forum activity for this year centred on the General Practitioners (GMS) contract, which was introduced from 1st April 2004. Six forum groups found that local people were not informed of the new procedures, even at the most basic level. Others areas highlighted in terms of activity for this period were continued improvements to knowledge, learning from PALS and complaints and the Independent Conciliatory and Advisory Service (ICAS). There was also an added degree of work around local hospitals and joint working with the local hospital Trust PPI forum, particularly in mental health, special needs and reconfiguration. Many local hospital health issues were pertinent to all forum groups and joint working meant a conceivable increase to the range of projects.

For the third year 2005 – 2006, the picture changes again. In five of the eight forums, membership was in most instances changing, and not least due to the abolition of the Commission for Patient and Public Involvement in Health (CPPIH 2004) and uncertainty about the Forums future. Any change to forum membership meant that activities were considerably implicated and even if numbers were maintained, forum members (6) advised that changes in the membership affected group dynamics, as time was needed for adjustment and integration.

Added to all this forum organisational change was the intended reconfiguration and mergers of Kent Primary Care Trusts, NHS and Ambulance Trusts and the Strategic Health Authorities, which inevitably would mean much larger Trusts and Authorities, plus a common overspend situation. At the same time as these financial structures were presenting themselves, the Primary Care Trusts were also coping with the newly introduced health philosophy of transferring the emphasis away from hospital-based treatment towards community-led care. Finally, this year, there was a review of the patient and public involvement forums conducted by an Expert Panel, reporting to the Department of Health (Department of Health 2006). This panel would debate the options for PPI forums and would be involved in the final recommendations that would affect the forum group's very existence.

Interesting points from the 2005-06 annual reports were the apparent consistency of contacts and presentations within the community to improve the profile, although once again it is impossible to ascertain the actual level of this commitment. One group (Group D) were also particularly interested in equalities in health and continued to review Primary Care Trust services to ensure that equal services were available to all sections of the community regardless of ethnicity, gender or disability. Work was also completed by the same forum group to ensure that primary care trust staff members were culturally aware and respected the culture of all people within the community.

6.3.2 Forum Meetings and Agendas

This section highlights the detail surrounding forum meetings and agendas, which developed towards a more formalised structure over time. In carrying out their business, PPI forums could decide to hold formal or informal meetings. A formal meeting could be a meeting in public or an actual public awareness meeting on a defined subject, often with appointed speakers. An informal meeting is categorised as a meeting for forum members only, either a working group or informal gathering of members working on a specific project.

To hold meetings in public the Forums had to give at least seven days notice to the public and to members. There were no other legal requirements but the Commission strongly recommended that the meetings were open and answerable. From the annual report information available, all the participating groups increased the numbers of formal meetings year on year, as shown in the following summary (table 6.3 below). From collated forum respondent interview data covering all eight forums and the researchers own meeting observations however, very few members of the public attended. As indicated previously, the increase in meetings is set against the knowledge that both the Commission for Patient and Public Involvement in Health and the PPI forums would be abolished and with little concrete information on the future.

Table 6.3 – Summary of Forum meetings held 2003-2006 – (Detail from Forum Annual Reports)

Forum Group	2003-04	2004-05	2005-06
Group A	Formal: 0 Informal: 4	Formal: 1 Informal: 10	Formal: 8 Informal: 2
Group B	Formal: 1 Informal: 5	Formal: 4 Informal: 7	Formal: 11 Informal: 1
Group C	Formal: 2 Informal: 4	Formal: 5 Informal: 5	Formal: 7 Informal: 7
Group D	Formal: 1 Informal: 4	Formal: 10 Informal: 1	Formal: 10 Informal: 1
Group E	Formal: 1 Informal: 4	No information available	No information available
Group F	Formal: 2 Informal: 1	Formal: 6 Informal: 8	Formal: 10 Informal: 8
Group G	Formal: 2 Informal: 4	No report available	Formal: 7 Informal: 0
Group H	Formal: 3 Informal: 0	Formal: 10 Informal: 1	Formal: 11 Informal: 0

For the meetings in public, members could only make a decision if a majority of members agreed, but interestingly, this majority equally meant those not present at the meeting. So apart from needing a majority vote, there was no actual rule about needing a '*quorum*' of members to run a meeting in public. From the six observed meetings, however, not all groups were able to proceed normally as so few members attended. Although the forums were not required to have a standard quorum of people at meetings in public, or necessarily elect a chairperson, the scenario was in practice, very limiting for the public attending. Matters of forum business could often not be agreed and the process certainly did not always give the impression of a professional group with the powers to make some difference to local health services. The majority of the groups did have a regular chairperson, who appeared from researcher observations, fundamental to the success and progression of forum business. As identified in Chapter 5 however, there was a formal lack of arrangements for leadership, which is identified as important to bring cohesion and consistency to members (Hogg 2007).

So why, and in what senses, were some of the PPI forums more successful than others? The following detail draws on some comparisons to answer this question:

From the data collected, three of the groups (B, D and F) appeared to develop their work programmes more extensively. All of these groups appeared to have developed good working relationships with their respective Primary Care Trusts. Group F, in particular, set out an ambitious agenda of work, which culminated in the publication of findings available on the Primary Care Trust website, and a positive response to a community health day, which had over 500 attendees, and was supported by local industry and the media. The group recognised their success by detailing information in the ongoing annual reports, although this appeared to develop year on year, presumably, as they grew in knowledge and confidence. The following are also possible indicators to their particular success:

- The group had a relatively stable membership, and also retained the same Chair over the period and this retention, stability and consistency were important factors
- The Chair made a large commitment in terms of hours, had a long history of interest in the subject, and regularly attended the Kent-wide Chairs network
- The group had a good relationship with their Primary Care Trust, regular meetings were held between the Trusts Chief Executive and PPI lead, the PPI forum Chair, and the Trusts own patient group Chair to progress ideas and improve communication
- Many group members had come from the former CHC or from a professional background and had a good knowledge of the NHS system and NHS terminology
- This forum group also had a wide involvement network, (with a separate working group working specifically in this area of development), consistently attending other group and club events, actively seeking local views on health services. This wider community network (including contact with youth groups) was obviously a key indicator in gauging a wider community perspective. The PPI forum members then discussed this community feedback, and from there decisions were made on inclusion to the work programme. Sub groups also met regularly outside of the main meeting
- The group evolved structures over time and considered what worked and what did not. An example of this was an innovative scheme for collecting patients' experiences through a Health Link Reporter Scheme, whereby local people *'reported'* on the NHS, rather than solely relying on patients and the public attending meetings, events or linking with members. Other local PPI forums developed similar schemes following this introduction

- Overall, this group had relatively good attendance from the public at open meetings. The group also actively worked with the local hospital group and developed some cross working with other neighbouring forums
- Apart from public meetings the group published news-sheets, had presentation events and jointly commissioned research with a university. The group established successful ongoing media links

This emphasis on the local and regional media could have been a crucial component in ensuring the wider circulation of information and the few groups (like Group F) that actually achieved this appeared to have had a more prominent profile in their communities. Health issues are often newsworthy as they affect a large number of the population, even at a local level, particularly given the large-scale changes, concerns and hospital closures that appear regularly in the news. Apart from influencing the local health processes, presence in the media it could have been a vital means of raising the profile of the forums. Other authors like Newman (2001) and Baggott et al (2005) have noted the importance of the media and highlight that no group wishing to influence public policy can really afford to ignore it.

An amalgam of themes and topics were summarised from the agendas of the six forum meetings attended and observed. It is recognised, however, that these details are a snapshot, at this point in time, but nevertheless they give some indication to the work programme undertaken and the means by which the forums sought to define, undertake and make meaningful its responsibility of representation. Some topics remained unaltered or were unfinished and there was no obvious priority in terms of the attention to these topics within each group.

From the meeting agendas of all the forums studied, there were three main priorities; annual report or future work plan details/updates, work projects within general practice and finally Primary Care Trust mergers/reconfiguration. The first priority links to the annual report detail on activity as some topic areas remained on the work plans, as they were unfinished, sometimes from year to year. This also has bearing on the detail from the interview data as time commitment, and recruitment and retention were ongoing problems, which ultimately affected the number of projects and activities that could be completed or indeed ideas taken on as new work from year to year. Indeed, many projects appeared to be ongoing, and this reflects the conclusions of the data in Chapter 5, with reference to the recruitment and retention difficulties compromising and limiting the work completed.

The second priority was continuing work in general practice and again this linked back to report and interview data. This area was seen as a priority, and influenced the Forums given the General Practice contract and the government's new agenda and philosophy to transfer some hospital-based treatments into Primary Care. Many PPI forums found that their local population were not aware of the new procedures and any possible implications this would have to their healthcare.

The third interest area was the mergers of Primary Care Trusts and the reconfiguration of the health service. It was a clearly influential and a topical priority for the groups, and one that had developed substantially since the collection of the questionnaire survey and interview data. The subject was also highlighted in some detail within the final year of PPI annual reports (2005/06) analysed for this study. Many Primary Care Trusts were facing overspend situations which in turn led to Trusts having to make firm decisions about services and the future. The new philosophy, (as above), of transferring emphasis away from hospital-based treatments also meant some hospital ward closures. In addition, the first stage of the 'Choice' agenda had been introduced, whereby patients could choose where to be treated, with the funding following the patient. Just to add to this period of change, it was revealed that the NHS was to be restructured with much larger Trusts and Strategic Health Authorities.

6.3.3 Time Commitment

As highlighted in Chapters 3 and 5, forum members were expected to spend between two and three hours per week on forum activities. The Commission recommended that the members each had an area of responsibility so that they were not all spending the limited time doing the same thing. Many members, however, far exceeded these recommendations detailed within the member handbook (CPPIH 2004). It is also important to note that meetings held in public could be two-three hours in duration alone; therefore giving no further time to progress ongoing or planned issues.

The Commission felt that many people resigned as the commitment in time was far greater than first envisaged, although acknowledged this could have been made clearer at the initial interview, particularly as retention became an ongoing problem.

"There were issues about time commitment, and people have resigned as they felt it was a much bigger commitment than first realised, so this continues to be a challenge, but the Commission will work with the forum groups and FSO's to tackle the situation" (C1)

Twenty-five forum members interviewed indicated that it was not unusual to complete in excess of the advertised hours. Members from four groups identified that they regularly completed ten to twenty weekly hours, including communications and the volume of paperwork that was distributed. On checking with twenty-six of the participating forum members interviewed (all groups), the consensus was that hours committed were variable but far exceeded the stated hours.

"Most of us are finding that our few hours are turning into a full-time job. It can seem quite a burden at times and easily takes ten hours per week plus" (16)

Ten respondent interviewed indicated there was a small proportion of very active members, but equally there were also inactive members, whether from lack of time, other priorities, ill health or simply committed to only achieving the hours agreed in the recruitment process. The implications on limited hours and lack of clarity on hours had a knock-on effect on the level of workload and perpetuated the difficulties, as identified by Hogg (2007), *'It is one thing to turn up at a meeting but quite another to collect patient and public involvement views, a tough and time-consuming task'.*

The majority (25) of the forum respondents interviewed commented that unless a health issue directly affected your life, you were unlikely to be motivated to spend time at meetings discussing local health issues. Very few members actually kept accurate records of the number of hours they contributed and this formal auditing may have been useful when attempting to persuade future governments or authorities of the seriousness and commitment of voluntary members and the necessity for community groups of this kind. Perhaps this inability to describe and quantify the workload meant members were disadvantaged in understanding the real implications of forum membership. Almost exclusively (22) respondents interviewed indicated the necessity of increasing the membership numbers to cover a larger NHS perspective.

6.4 Forum Member Future Expectations for Forums

The final question in both the questionnaire survey and the interviews was an invitation to forum respondents to state their expectations for the future of patient and public involvement forums. Respondents had framed these expectations based on their previous and ongoing experiences of health service issues. Respondents added a total of ten labels to describe their forum expectations, (see summarised table 6.4 below), and shown in full as Appendix 11). Although there was a mixed response with a range of issues for each member, the researcher made the decision to highlight and discuss the top three expectations in more detail. All the respondents interviewed (27) indicated that they had high initial expectations for the PPI forum groups.

Table 6.4 Summary of Data form Survey - Question 9 – Future Expectations for PPI Forums

Forums		Influence	Patient/ Community Independent Heard & Listened to	Improve NHS Services	Understanding NHS Organisations	Improved Community Engagement	Other Expectations (amalgamated)
	Persons						
Group A	3	1	2				
Group B	4		1	1		1	1
Group C	7		1	3	1	2	
Group D	4		1	2			1
Group E	4			3			1
Group F	6	1		2	1	1	1
Group G	5		2	2			1
Group H	7			6		1	
Totals	**40**	**2**	**7**	**19**	**2**	**5**	**5**

The key expectation from nineteen of the forty forum members surveyed, which was the prime purpose of almost half of the respondents', was to *'improve national health services for all people within their community'*. On discussing this rather ambitious expectation further at interview, the consensus was that health services were not adequate and although this expectation was effectively the Primary Care Trust role, services needed general improvement particularly in funding, availability and accessibility of services. Thirteen members interviewed discussed the often limited services perceived for older people, in particular, or in specific sections of the community but only within the health care structure. There were no discussions on social care or other related areas and other authors (Banks 2001, Baggott 2005) have commented critically on patient and public involvement being too NHS-centred. The emphasis on older people with the health system clearly had bearing and this was possibly due to the actual age ranges of the forum membership. These perceptions on health service limitations were often from personal experience, this at times being one reason for joining the PPI forum or alternatively from press related information.

Secondly, eight forum member respondents to the questionnaire survey and interviews expected the forums *'to be independent, heard and listened to'*. These members felt that forums could only achieve their role if they remained independent. Forum independence or perceived independence was discussed further and these members identified independence in terms of linkages to representing the community and democracy, in ensuring that the patient's voice was heard, and in order to counteract the power of professionals. There was also comment, as reviewed in Chapter 2, on the perceived potential benefits to involvement and the NHS principle of equal access to treatment for equal needs (Klein 1993). Independence was also identified in the context of the future appointment of chairs (see Chapter 5, recruitment and appointment of chairs). PPI forums, although outwardly independent, could easily be seen as appointed bodies, possibly due to the Commission's funding links with government. Cooke and Kothari (2001) commented that state sponsored participation is open to accusations of manipulation, cynically supporting management rather than actually enhancing democracy.

Following this theme of being '*heard and listened to*', six respondents interviewed also commented on how difficult it was to be part of a decision-making process with the Primary Care Trust. Members often felt they were invited and told of the decisions rather than being part of the debate. The consensus inevitably, was that this meant the Primary Care Trusts were able to '*tick boxes*' stating that the Forum was part of the decision-making process.

> *"They (PCT) might ask for views on something by saying "we are going to do this, what do you think". They should say, "This is what we would like to do, what do you think", the professionals are making the decisions and are not concerned what people think'" (37)*

It was recognised by four of the respondents that it could be difficult to retain independence and credibility if entering into partnership working with Trusts. The mere fact of attendance at a Trust Board meeting may constitute agreement and hence the concerns of the forums needing to maintain neutrality. Other respondents (3) were happier to attend Board/Trust meetings, to give an opinion, but not to have voting rights so that the loyalty remained with the Forum and there was no conflict of interest. Independence therefore, in this scenario appeared to be more linked to conflicts of interest and concern about misinterpretation, which could, in part, be due to a lack of relationship or no definition of working boundaries between the Forums and the Trusts or a clear sense or identification of each other's responsibilities. Fundamentally, this conflict of interest was surprising, as for Forums to make any difference, there would be a necessity to fully contribute on behalf of their communities. Hogg (2007) has also discussed whether patients/public could become '*insiders*' and partners of managers whilst retaining their independence.

"We should be involved ourselves, keep our independence and should go our own way" (15)

There were also clear political and resource constraints placed on the Commission for Patient and Public Involvement in Health, which only adds to the view that the structure lacked true independence, although the Commission was established to ensure independence and give credibility to the forums within the community. An essential requirement for independence, as indicated and confirmed by Hogg (2007) is the importance of having your own staff and control of the money and most importantly stability. As identified previously, all of these appeared lacking in terms of the PPI forums researched.

The final main expectations were for '*improved community engagement*' and forums were seen as key in achieving this, particularly given their regulatory brief. Five forum member respondents, however, acknowledged that the change to the PPI structure, particularly following on from Community Health Councils, was unlikely to promote genuine engagement of local people. Small-scale changes were identified as important, particularly around the importance of advertising PPI forum existence, and in developing and encouraging organisations to involve and engage with patients and the public more effectively. However, half of the members interviewed (14) were unsure how patients and the public could be expected to understand the PPI structure given the separation of forums for primary and secondary care, ambulance and mental health Trusts. If a patient had an issue how could they understand that there are differing forums, highlighting the fact that the PPI formal structures were too complex for the ordinary lay individual to understand.

"In terms of the forums, what do they do, who are they and which forum should I go to as a patient" (F3)

The PCT professionals were much more resolute in their overall approach to PPI forums. The majority (6) felt that the concept was a good thing but were uncertain in the definition of the forum member role.

"I would like to work much closer with members on setting objectives and work plans as the PCT would like some shared ideas particularly where the PCT knows matters are not that good, so that we can work together through joint consultations and finding solutions" (PH)

"The forums should have more of a strategic and monitoring role, perhaps in ensuring PCT compliance with Section 11. The government could identify what patients are concerned about and instruct patient forums to follow up specific areas with their respective PCT's, this would be a fair agenda for them" (PI)

In summary, many of the forums did attempt to expand their activities and work plans year on year. There is also no doubt that the limitations of forum member time together with the ongoing recruitment problems severely limited the impact of these plans. All forum groups were broadly similar in consistently attempting to raise their profile and in their development of contacts year on year. Similarities also extended to the majority of work being conducted within general practice, in part, due to the introduction of the new GMS contract.

6.5 Conclusions

This second results chapter, presenting more findings of the fieldwork, has been concerned to paint a picture of forum group process and activity. It has also identified the forum relationships with the local professional organisations, in particular the respective Primary Care Trusts and the Forum Support Organisations.

The findings in this section, based on networking, contacts and activities suggest that:

- While forums attempted to raise their public profile, nevertheless public attendance at meetings and overall progress remained limited, apart from one particular forum
- Activities and work increased in line with knowledge and understanding, and members took responsibility for work projects as work plans increased
- This activity continued despite the uncertainties regarding the future of the forums, due to the announcement of the abolition of the Commission (CPPIH 2004)

The data suggested little change in the overall number of members active in each Forum, at least in the majority of groups studied in this research. However, these numbers mask the serious retention problems, and it is clear from the data that there had been much more significant change in actual Forum membership over the first three years of their existence, than the official statistics revealed. The extent of membership turnover had repercussions for the forum groups, the changes delaying or limiting overall group development in working and getting to know each other or building a cohesive team and in the collective view of local health issues. Ultimately, this recruitment and retention had profound effects on the work plans and agendas, as members had very differing levels of skills and experience. A longer timeline for development could have meant that the volunteers recruited were entirely suitable and had full understanding of what was expected. The type of recruitment and interviewing processes adopted gave little opportunity to assess the skills or aptitude of the potential members, again having a potential knock-on effect on the level and type of forum work completed.

The findings on meetings and agendas show that the majority of the forum group activities centred on work in general practice (GP) services and in particular, around the new GMS Contract, and the reconfiguration and mergers within Kent Trusts. Other common activities, similar to national statistics, were around out-of-hours services, health information and mental health services (CPPIH 2006). The PPI forum activities and work plans were generally limited with differing levels of success and influence, differing levels of public interest and often lack of real Primary Care Trust attention. As indicated previously, Trusts would often amalgamate patient and public involvement around another work role or commitment. Chisholm et al (2007) commented that a survey of Primary Care Trust managers revealed that PPI forum groups were considered less likely to be influential in commissioning decisions and much less influential than other voluntary or patients' groups.

The formal relationships that were intended between the PPI forums, the Forum Support Organisations (FSOs) and the Primary Care Trusts were also reviewed in this chapter. The data in this study found a mixed reaction to the forum group relationship with their FSO (administrative) support. These comments centred on a lack of real co-ordination and accessibility, which had some bearing in this research, as the two identified Forum Support

Organisations worked quite differently, and were not easily identifiable. The Commission regional office was responsible for the performance management of the FSO's, and there has been some evidence nationally (Health Committee 2007), that there were also differing levels of national support for FSO's, particularly financial, although they were all providing the same service. From the outset the forum support organisation role was also not abundantly clear, was it purely administration, as detailed in the Scope of Work (CPPIH 2003) or could they advise members on basic training or strategy, particularly as many volunteers had limited knowledge of the NHS.

The Primary Care Trusts also had varied working relationships with the FSO's, although half indicated that they understood '*each other's way of working*'. From the FSO scope of work (CPPIH 2003) there is little detail to indicate a definite requirement to work specifically with the Primary Care Trusts, other than in facilitating communication between Forums and health organisations, but this development of relations between all parties could have been fundamental in progressing and expanding the Forum profile.

The majority of the Primary Care Trusts interviewed had their own patient forum or internal collection of people, which meant conceivable duplication of effort. This adds further weight to the comments from other authors, for example Baggott (2005), about the lack of clear thinking to ensure the various initiatives did not undermine each other. The Primary Care Trusts indicated mixed reactions to the role of the PPI forum groups and in general the picture was not one of clear effective working, with many groups seen as having a different interpretation and limited knowledge of the health service.

There was one notable exception in this study, however, and this forum group (Group F) was one of few that benefited from having a Primary Care professional working specifically in patient and public involvement. The Primary Care Trust advised that the Forum was fully integrated with the Primary Care Trusts own patient group and that meetings and liaison were constant. Networking evenings for both groups and the local hospital group were held together with a Chairs group (made up of all three groups), with the aim of co-ordinating the workload. Overall, the Primary Care Trust evaluated that the Forum was doing well, but needed further development in more formal aspects, like report writing.

As a point of reference, this forum group retained a more constant level of membership over a longer period and retained the same chairperson experienced in the health service system and terminology. This group also had a wide community network and evolved structures over time to accommodate a range of means to communicate locally. The group developed schemes for collecting patient experiences, which were then adopted by other PPI forum groups and developed a pro-active relationship with local and regional media, which culminated in the group receiving an accolade for their outstanding work during 2004/05. The accounts of this forums success were documented in successive annual reports but it was not until 2005/06 that the group specifically itemised areas in their annual report that "we are proud of". These accounts included specific health events, survey details and recommendations, on a variety of local health issues and it would appear that the numbers of attendees or contacts were considered by the group as an important measurement, as was the range of local health issues.

The Forum Support Organisations, Commission for Patient and Public Involvement in Health and PPI forum members all indicated that the Primary Care Trusts were working differently. However, the Trusts were also seen as being key participants to the local progression of patient and public involvement. Warwick (2007) commented on the time needed to develop a relationship with the local Primary Care Trust but also that a Trust could easily say they were involving forums, without actually entering into any meaningful dialogue. There were some supportive comments about PCTs, but this indifferent approach was felt by some forum respondents in this research, which can potentially limit rather than expand the extent and impact of patient and public involvement.

As the evidence has indicated, the PPI forum groups in this research appear to have had limited impact collectively within Kent, based not only from the responses of the forum members but also the responses from the Primary Care Trusts, other related organisations and their general low profile within their communities. The forum members were generally invisible in their locality, and often had no previous links to either the health service or voluntary sector and so were more peripheral to the politics of the local economy. They were not appointed or elected and did not have their own office or backing of a solid staff structure. For members of the public to make contact was not straightforward, and this could only be made via the Forum Support Organisation, as no member names were publicly available.

However, it is recognised as detailed earlier in this chapter, that some Kent groups had more defined success completing useful work on local issues and interacting well with Primary Care Trust professionals. It is clear that patient and public involvement in health will only prosper if there is a baseline of professional willingness, and for members of voluntary groups to recognise the differences in their perspectives, roles and abilities. Involving local people in PPI Forums was clearly much more difficult than government or the Commission anticipated, with decisions often being made quickly, without an understanding of the likely implications. Hogg (2007) commented that the nature of representation, accountability and governance were never addressed in PPI forums, and this research evidence suggests that the forums were left conceivably open to criticisms of being undemocratic, unrepresentative and inconsistent in the majority of cases. However, PPI forums groups certainly did not have much time to develop or get to grips with their role and in spite of all the aforementioned difficulties raised in this research, many very dedicated volunteers gave a huge time commitment for the benefit of their local community.

The next chapter draws together conclusions of this research and indicates how the experience of PPI forums might hold lessons for the future.

CHAPTER 7

DISCUSSION AND CONCLUSIONS

7.1 Introduction

This final chapter returns to the research questions posed in the first chapter with the purpose of drawing together the key themes and messages identified. It also places the findings of the study against the established bodies of knowledge and the conceptual framework reviewed in Chapters 2 and 3.

This research study has been conducted at a time of very significant change in health and public services, and indeed in the governance of these services as Newman (2001), has observed. As Chapter 3 described, the government agenda has clearly emphasised, at every opportunity, the importance of patient and public involvement in the development and delivery of health services. The NHS Plan for England (2000) responded to media criticism about the governments handling of the NHS and promised a new system of patient and public involvement, this reflecting a broader commitment to participation in public services and citizenship (Newman 2001). Policy reforms in the health service, and those in local government and other sectors have therefore included provisions for involvement at all levels of governance (Stoker 2005).

The removal of the 'semi-professional' Community Health Councils (CHC) and the emergence of the Patient and Public Involvement Forums seemed, then, to signal a major development in the relationship between the NHS and civic society. CHC's had been formed in a different manner to Forums, with paid officers and a large network of volunteers or co-opted members. The CHC role was meant to assist, advise and consult patients/consumers, although in practice, their role centred upon pursuing individual complaints and speaking on behalf of communities in formal consultations.

In 2003, the process of recruiting local people to Forum membership started. This research aimed to assess what happened as PPI forums were established and started to operate. Specifically, and as summarised in Chapter 5, the study sought to identify:

- The composition and profile of Primary Care PPI Forums
- How the PPI forums were constituted, their activity and support
- How the PPI forums related to Primary Care Trusts and other organisations
- In what ways the PPI forums represented their communities

The study reports details of the volunteers who formed the body of the PPI forums over the study period, about volunteer member reasons for becoming involved, about the process and experience of recruitment to the Forums, the training offered and undertaken, and about member's understanding of their role as '*representatives of their communities*'.

PPI Forums were both independent of the NHS and composed solely of lay members and so provided two potential lines of development: first, a basis of improvement to health services through means of inspection and scrutiny, involvement in review, planning and design of services, and second, strengthening the democratic engagement of local communities, on matters of public policy. Chapters 1 and 2 recognised this new twist to patient and public involvement. The democratic approach and the contribution of forums should relate to participation and contribution within society, but there are inherent tensions between representative and participatory democracy. Participation can also be seen differently by those in power who invite participation, and by those who are invited to participate.

The restriction to lay membership and knowledge and the commitment to community representation were crucial elements to the design of PPI Forums. Institutionally, the Forums related directly to NHS Organisations – the Primary Care Trusts, and complemented the other elements of governance – the Trust Boards, which also included lay non-executive members, the Trust systems for handling complaints and patient involvement, and the Local Authority scrutiny function, all of which feed into service design and evaluation. They provided opportunities for a collective '*community*' presence in the system of governance and this raised questions about how a standard distinction (and choice) between representative and direct democratic mechanism for governance had been reviewed in the design of PPI forum policy.

This study was carried out amongst a continual process of change and indecision around the whole PPI forum concept. Finally, it has been able to observe the debates about the transition to a successor system of public involvement, LINks. This chapter, therefore, also reviews the experience of the establishment of the PPI forums, against the original expectations, and looks further forward to draw out learning and conclusions for future policy.

7.2 Discussion

7.2.1 The Composition, Profile and Activity of the Forums

As Chapters 3 and 5 have described, PPI forum groups were formed in a manner specified in legislation and were all subject to certain rules and statutory powers. The Commission for Patient and Public Involvement in Health had responsibility, in law, for establishment of the Forums and for the recruitment of volunteers to Forum membership. Two key

Statutory Instrument documents, 2123 and 2124 (NHS 2003) set out the membership regulations, procedure regulations and the functions for PPI forums. These Statutory Instruments indicated that an expected forum member should be either a patient or user of health services, who lived in the same locality as the Primary Care Trust or a member of a community/voluntary group, which was established to promote the interests of others. The whole was aimed at representing patients and local communities in the planning, management and scrutiny of local health services. There were also exclusions, and in particular, NHS personnel. This formal setting out of eligibility for Forum membership (and exclusions) presumed much about the nature of community, the expected membership, and about the readiness of NHS organisations to respond to the volunteer groups.

As indicated in Chapter 2, the Forums were created to represent the views of the local community, and this data has suggested that in demographic terms, the process of recruitment could be argued to have achieved the minimal criterion of representativeness in the composition of the forum groups. Although it has made only crude comparisons between Forum composition and population demographics, the research has found i) that the gender balance was equal amongst the participating forum groups, ii) that the age range of the volunteer membership was heavily skewed to the over 50s, and iii) that this data followed a similar south-east regional pattern. The ethnic mix of the forum groups was proportionate and matched the demographics of the region; however, this did not necessarily mean this translated down to local community structures given the small numbers of forum members, the uneven distribution of minority ethnic population groups and the dynamics of a changing population.

Such an analysis of representativeness takes conventional administrative boundaries to be a reasonable approximation of community, although as the discussion of '*community*', also in Chapter 2 suggested, taking such a definition as writ may have significant implications for outcomes that can be achieved, even if there are competing definitions that might also apply in practice (Jewkes and Murcott 1996, 1998). One particular line of argument that this research has suggested may be important here, and concerns the way in which being a '*representative of the community*' is understood. Although demographic, or descriptive, representativeness is one possible criterion, other criteria can be found in the manner and process of representation.

Chapter 2 also discusses Etzioni's (1996) communitarian thesis about '*the responsive community*', which argues that '*authentic communities*' are ones that are responsive to the '*true needs*' of all community members. Indeed, half of the forum respondents in this research had high initial expectations for PPI forum groups and wanted to 'improve the NHS for all people within their community', highlighting a consensus that health services *were not adequate for all and needed improvement in funding, availability and accessibility.* This reflects the instrumental purpose of PPI forums and other forms of patient and public involvement in health, and may also have implications for the design of PPI forums as a means of strengthening democratic governance. However, this analysis says little about the processes by which needs are expressed, or about representation. As in other critical assessments of '*community*', the question of the boundaries of affliation and identity between and within communities is of importance in Etzioni's analysis. Although the administrative definition of community gives a clear rule for adjudicating geographical (i.e. community) affiliation in the selection of members for PPI forums, representativeness begs questions raised in political theory, discussed further in Chapter 2, about the categories by which representatives are said to match their communities or '*constituencies*'. Political theory distinguishes between a politics of presence, in which representativeness is the primary criterion, and a more active form of political engagement, in which processes of representation are given particular emphasis.

The politics of presence was unlikely to work for Forums. Whilst Kent PPI Forums members emphasised the importance of the foundation principles of the NHS and the democratic right of equal treatment for all, the inclusion or reflection of all possible sections of the community in the membership of the Forums would be unlikely. In addition, is descriptive representation necessary? In developing the idea of '*preferable descriptive representation*', so that representatives reflect better, the community and its variety of member categories, Dovi (2002, page 729) asked, *"Will just any Woman, Black or Latino do?"*. Dovi appealed not to a greater specificity of identity, but rather to the capacity of representatives to represent and carry out accountability. *"Preferable descriptive representatives (should) have strong mutual relationships"* (Dovi 2002, p.729) with the group's they are appointed to represent. This criterion links the complex issues of identity to equally difficult issues of the quality of access that is available to groups within communities. Dovi (2002, p.742), concluded, "*The extent to which a politics of presence can include those who have been systematically excluded from political life is also the extent to which a politics of presence can bolster democratic participation and the legitimacy of democratic institutions*".

These issues of identity and motivation, and the conceptions Forum members had of their role as representatives, were addressed in this research. The research looked at two sides to this question: the first concerned the means by which individuals became aware of the

Forums as an opportunity for active engagement and the terms in which they understood the Forums (the 'pull' of the Forums); the second concerned their motivations for applying and making the commitment (or 'push') to serve.

7.2.2. The 'Pull' of the Forums

The Forums were established to replace Community Health Councils (CHCs), who were set up in 1974, to give patients a voice and to act as a local NHS 'watchdog' (Warwick 2007). The limited research on CHCs, reviewed in Chapter 3, showed that the effectiveness of individual CHCs depended largely on the energy and commitment of the paid officers (Klein and Lewis 1976, Hallas 1995). Although Warwick (2007) found that few CHC members went on to serve in Forums, this research revealed a high number of ex-Kent CHC members in the membership. Indeed, one of the Kent Forum Support Organisations was formed by ex Community Health Council officers, which may have had bearing on their contacts, networks and encouragement to the new system. Chapter 3 also indicated that the PPI forums were set up with no choice on either their Forum Support Organisation or the staff provided for them, and therefore advice and support was uneven across the forum groups.

The Forums were not strongly advertised and promoted within the local communities from which volunteers were sought. Regional media were used by the Commission for Patient and Public Involvement in Health to recruit members, but advertising campaigns were kept centralised, in general, or were generated via the Forum Support Organisations (FSO's): the forum member's sense was that neither route created a high profile. Members reported that prospective volunteers would only know about the Kent PPI forums if they were personally aware of these opportunities to influence and contribute to health service governance. This awareness was commonly the result of a former background as a health service volunteer, a Community Health Council member, or occasionally the result of a positive or negative experience in health. The Commission for Patient and Public Involvement in Health reported that Kent was no different in this respect to other regions.

Baggott (2005) and Warwick (2007) have commented on the overall costs of the PPI forum system and the pressure of recruiting over 4,000 people in less than nine months, with groups often struggling to meet minimum numbers. Other authors have reported on the under-resourcing of the PPI forum system (ACHCEW 2002b, Baggott 2005) and of other community involvement efforts (Maguire and Truscott 2006). The lack of budget allocation to support and sustain each Forum and the lack of staff employed to support Forums, did seem to have contributed to problems in attracting and recruiting members. There also appeared to be some doubt about the requirements needed to undertake the work and about the person specification for this role: no clear and designated parameters were identified. Many of the Kent respondents advised of poor recruitment practices, with many expectations of a more formalised process of selection, following recognised good practice (OPCA 2002). Recruitment was not just a teething problem: as membership numbers continued to fluctuate, reflecting an ongoing difficulty with recruitment and retention. This ultimately impacted on the forum work schedule, limiting the issues that could be addressed and the extent to which a credible input to the Primary Care Trust could be made.

Although members may have spread information about the Forums through their own personal networks and community affiliations to invite applications for membership, recruitment activity by the Forums themselves was essentially restricted to raising public awareness of the Forums. The data on networking and activity suggests that the PPI Forums did attempt to raise their profile within their respective communities but, apart from one forum, public interest remained limited. Studies of recruitment into social movements (Diani and McAdam 2003) have emphasised the importance of networks of association, through which existing members draw new members along a pathway from tentative or limited commitment to more committed involvement within the organised activity. The PPI Forums were clearly different to voluntary social movements in two ways: first, the lack of a gradual pathway into activity and, second, the strict and formalised regulation of membership.

In the majority of Forums, where the membership levels would allow, activities and work plans increased in line with improved knowledge and understanding. This was despite the uncertainties on the future of Forums, in particular when the abolition of the Commission was announced. The Forum activities and work plans had differing levels of success and public interest, but three Forum groups in particular worked at developing programmes of activity. One group also confirmed good and ongoing levels of attendance at public meetings. The difference with this particular forum group was that a core base of members and the Chairperson remained stable throughout the period, and they specifically set out to prove themselves a credible group, working closely with their Primary Care Trust. The group also had a wide involvement network actively seeking local views on health services and evolved structures over time and considered what worked and what did not. From the ongoing annual reports, the group also took pride in their success, and was one of few who used the local media to ensure a wider circulation of information and to improve their profile, realising that local health issues are newsworthy, and of interest.

In summary, the forum groups within this study were broadly similar in their composition particularly with regard to ethnicity, gender and age ranges. Recruitment processes were limited and problematic, and these had obvious effects on membership numbers and work programmes. This selection of individuals was important to reflect a wide range of knowledge, skills and competencies, particularly given the nature of the forum responsibilities and the necessity to represent a constituency. Retention of members was another ongoing problem, due in part to unclear interviewing processes and the time commitment to Forums being far greater than first envisaged. However, the number of people that give up substantial amounts of time to sit on this type of PPI structure may always be limited (Coulter 2006). It is, however, somewhat unfair to be judgemental on the overall work of the Primary Care PPI forums. From the details and results, they did not have much time to develop, and had to contain some scepticism, disruption and probable dashed expectations in many cases.

7.2.3 The 'Push' to Participate

As indicated in Chapter 2, and as other studies of voluntary participation in community life, leadership and representation have shown, motivations for involvement are varied. In their study of public participation in local government, Lowndes, Pratchett and Stoker (2001) noted a difference between the explanations professionals gave for public participation and the reasons lay community volunteers offered. In particular, whilst personal experiences of services were reported by members of the public to be an important motivating factor, it was not, as the professionals suggested, their primary motivation for involvement. Gaffney (2002) in her unpaid community worker study also found that "*There was a strong adherence ....to the value of community, social justice and* *the importance of working with other community members ...there was an overall idealism or belief system about community involvement that was clear and distinct from personal motivations"* (p.13). Participation or involvement is therefore not provoked by a simple response to an experience (good or bad) of a service but by a complex mix of personal, social, political and moral values. From this research, few forum members admitted any form of personal agenda, and the majority talked of their interest in community issues and reported that they were happy to contribute to a service that they believed in with a common aim of improving the National Health Service for other people. Forum members also reported that they were able to be involved following retirement or semi-retirement, having time when health issues may have seemed personally important.

Patient and public involvement – like democracy – is often viewed as an intrinsic good (Florin and Dixon 2003). Others suggest that its outcome is symbolic (Arnstein 1969) or that it is an instrument to inform decision-making, rather than as a process, that actually devolves power to local communities (Rowe and Shepherd 2002). Other authors go further still (Harrison and Mort 1998, Redden 1999, Lupton et al 1997), suggesting that involvement initiatives may be used by governments to contain criticism, and give legitimacy to otherwise unpopular policy decisions. Walt and Nolte (2006) do suggest however, that more recent research provides a much more optimistic view, contributing to improvements in accountability within the health care system (Department of Health 2004).

In terms of retention, the voluntary status of Forums was also important to the Kent PPI forum members. Members were actually recruited with an expectation that they would be available for two or three hours per week. In practice, and as indicated in the last chapter, members reported that rather more hours were required to fulfil the responsibilities and expectations placed on the Forums, not least by themselves, as personal expectations for the groups were high. With a difference between the formal contract and the fundamental requirements of establishing the Forums, there have been some suggestions that there should be remuneration for time volunteered, in a similar way that non-executive Board members of Trust's, or citizen juries receive payment. Millward (2005) comments on the division between volunteers paid for their contributions, the '*elite volunteers*' and '*bog-standard*', the volunteers who bear the cost of participation. The Commission on the Future of Volunteering (2008) is clear in its manifesto that volunteering is an activity that involves '*spending time unpaid*', to benefit others, and that '*volunteering should become part of the DNA of our society*' (p.2). Offering a fee to people recruited randomly to represent their communities might have broadened the pool of applicants, but the fundamental independence of Forums could have been lost. Indeed, many involved in this study reported that they would not have been interested in joining if payment had been involved.

Independence or perceived independence was considered crucial in two other ways by Kent forum members: the future appointment of the Chair and the concern of credibility when working with Trusts. Most importantly, forum members felt that Forums needed to maintain neutrality. The complicated amount of NHS structures have also not encouraged or developed the Forum system. Indeed, and as reviewed in Chapter 3, PPI forums were formed alongside a variety of similar initiatives, like PALS, which only added to confusion. In Kent, there were not only these national initiatives but the majority of Primary Care Trusts had their own patient groups, adding to duplication and confusion.

Independence is therefore difficult when working within established and complex NHS structures (Hogg 2007).

7.2.4 Representing the Community

The concept of the forums as a neutral body of members, putting forward a democratic collective view was, in principle, thought by members to be a positive way forward, adding to the mechanisms by which communities could be assured influence with health care decisions in their area. As the review in Chapter 2 noted, patient and public involvement is also considered to be a way of maintaining social capital (Putnam et al 1993), achieving a cohesive society, and reducing social exclusion (Barnes 1999a). Lowndes and Wilson (2001) argued that the opportunities for public participation in local governance could shape the development of social capital and effect democratic engagement with local communities. Lowndes and Wilson (2001, p.633) emphasised:

"Four interacting dimensions of institutional design within local governance.... Relationships with the voluntary sector; opportunities for public participation; the responsiveness of decision-making; and arrangements for democratic leadership and social exclusion"

The following discussion focuses on the first and second of these, although brief comments are made on the third too.

The effectiveness with which the Forum members were able to represent their communities is not clear-cut, and there is some confusion, similar to Community Health Councils, about the representative nature of PPI forum groups. The Forum recruitment process was intended to result in a broad mix of individuals with experience of service use, and for them to be representatives of voluntary or community organisations. As Lowndes and Wilson (2001, p.635) note, similar to Forums, there is a tendency to "*prioritise the involvement of individual citizens rather than organised groups*". Hogg (2007) also commented that appointments to patient forums put value on the experiences of the individual user. Few Forum members referred to groups to which they were affiliated, from which they were nominated and to which, therefore, they would be accountable. Nor did they comment on the opportunities that these groups offered when seeking wider views on issues addressed by the Forums. In short, the relationships between existing community groups and the NHS, mediated through the Forums, seemed weak or absent.

Lowndes and Wilson (2001) also suggested that "*By providing opportunities for participation, local agencies can influence citizen's appetite for, and competence in, civic society*". This educative function of participation was considered in Chapter 2. This also brings greater legitimacy to public services through the evident responsiveness to expressions or representation of need. The complex set of expectations for the Forums – to be educative, to promote social capital and wider engagement with communities through consultation, and to influence public service quality – means that there was great emphasis on the character and commitment of the Forum representatives.

A common criticism of community representation in local governance mechanisms (Lowndes and Wilson 2001) is that places are filled by the '*natural joiners*' or the '*usual suspects*' (Maguire and Truscott 2006), who can be classed as unrepresentative due to their frequent presence, knowledge of the issues and understanding of '*the rules of the game*'. In fact, these individual have often learned to be highly effective representatives of their community, although this can go unrecognised (Millward 2005). There was no evidence to suggest that PPI forum members were seen as '*usual suspects*', but equally, there was only a reported limited connection between them and their communities.

The evidence from this study, as indicated in Chapter 2, is that Kent PPI forums group members often conceived of their local community in very limited terms, both in the numbers whom they felt they represented and in terms of the geographical area. Indeed, members were also divided as to whether they did, indeed, represent their communities, even when talking about consulting within small networks. Little et al (2002) have discussed the difficulties experienced by lay representatives in '*mixed*' lay professional forums, that may lead to representatives feeling they are unable to contribute anything but '*their own experience or view*' to policy making. The effect is to limit the wider attitudes and experience of those interests the representative is capable of speaking for. The Kent PPI forums did attempt to encourage involvement and there was evidence to suggest that all members had similar training opportunities and advice on engaging people from as diverse a background as possible, in terms of both encouraging extra membership and raising awareness on any health equalities or relevant demographics in relation to the local area. However, these were not taken up or widely understood by the general public. Measures of intent and commitment to formal representation, accountability or governance were difficult to find within the PPI forum structure. Hogg (2007) actually argues that these fundamental design principles were never fully addressed with the Forum model.

7.2.5 Relationships with 'Significant Others'

As indicated in Chapter 6, the eight Kent groups in this study had established differing relationships with the two Kent Forum Support Organisations (FSO). The two FSOs worked differently and were not known extensively by the public: they provided administrative support, and some development support to the Forums and their members.

There were also mixed relationships with the respective Primary Care Organisations. Some relationships appeared good, but there was a sceptical position, which argued that Forums were fulfilling a statutory role purely for the benefit of the organisation. Some PPI forum members in this research did not feel part of a decision-making process with the Primary Care Trust, other than to be fulfilling the PCT government obligation (Section 11) to consult (Department of Health 2001). In short, the Primary Care Trust had the *'upper hand'* in the relationship and the Forums served simply to legitimise a process. Members commented that the debate was generally over at the point of when they were requested to attend meetings.

As outlined in Chapter 2, various models of participation were reviewed that suggested a continuum representing developmental stages in involvement, as an example, in Arnstein's (1969) model showing non-participation to citizen control. In Arnstein's framework, the citizens start out powerless at the bottom of the ladder, which is propped up against the organisation where the power resides. It is up to the organisation to decide how far up the ladder the citizen can climb. More recently, Tritter and McCullum (2006) argue that it is the process rather than the outcome that has the greatest potential for changing organisational culture. Concentrating on the power dimension takes little account of diversity and equality and an empowering system needs to accommodate people with differing needs and possible dissenting views. The theoretical debates on ladders and continuums raise the question about how power can be afforded to lay members in the future. There is little doubt from the results of this research that there is a necessity to have flexibility and a system where lay people can join or become part of something when it is important to them. However, given the parameters of the PPI forum group success identified, there is also a necessity to have a core group of individuals that will be constant, be identifiable and foster relationships with both community and professionals.

Whilst Anderson et al (2002) comments that it is better to have a good consultation process than to offer partnership and fail to deliver it, there is little evidence to suggest that the Primary Care Trusts were strongly committed to the Forums as a means of consultation or indeed, as partners in local health service governance. Both PPI forums and Primary Care Trust representatives found it difficult to identify many positive, productive experiences of the involvement system. Picking et al (2001) mapped out the extent of the challenge to reorient statutory organisations structurally, culturally and professionally, so that they are better able to engage with lay communities.

In summary, the Primary Care PPI forums have had limited impact collectively within Kent, based on both forum member and professional responses. The groups were unable to reach a high profile within their communities, were not easily contactable, community networks were not extensive in most cases, nor were mechanisms in place to extend these. However, and as indicated previously, one group has had much more defined success completing useful work on local issues and interacting well with their respective Trusts and the local media. There are many reasons for the limited success but limited relationships within their constituencies and lack of overall professional commitment to patient and public involvement are fundamental to this outcome. It was clear that the attitude of the Chief Executive and senior team was vital in securing an organisational ethos and approach to the subject area. The Primary Care Trusts that had no dedicated visionary struggled to command seriousness or significance in patient and public involvement although, officially, each had a Board policy on the subject. Often the nominated professional role sat within a PALS or complaint structure, without a dedicated budget. The problem with this structure is realising that patient and public involvement should be everybody's business within the organisation.

For involvement to be worthwhile from a patient or public viewpoint, studies like Lowndes and Wilson (2002), Maguire and Truscott (2006) have repeatedly noted the self-evident importance of service responsiveness. Significant progress can also be limited by a failure to understand what effective involvement can bring to the NHS. Furthermore, the continual process of NHS change, including the reconfiguration of Primary Care Trusts, may also have affected the PPI groups in this research. As the Forums were tied so specifically to primary care organisations, these mergers had significant implications for the Forums, including the amalgamation of the PPI groups themselves.

Although it is acknowledged that a few individual Forums had credible success with specific projects, mystery and scepticism still surround the Forum process to some degree from both lay and professional viewpoints. However, the subject has still been progressed due to the forum groups, and has been kept on the political agenda.

7.3 The Future of Patient and Public Involvement

Less than five years after their inception, the PPI Forums have been disbanded and there is still some debate about what should have replaced them. The proposal to replace Forums with Local Involvement Networks (LINks), from April 2008, has been heavily criticised by the Commons Health Select Committee (Health Service Journal 2007). The Select Committee's reservations hinge on the premise that PPI forums should have been allowed to evolve and merge with the new proposed format, which would reduce the risk of losing volunteers.

The remit for Local Involvement Networks (LINks) will be with Local Authorities who also have the responsibility for social care, meaning 152 LINks in England. LINks differ from PPI Forums in that they cover a geographic area rather than being aligned to a health body (primary care, hospital, ambulance trust etc) and will be made up of individuals and organisations. LINks will also have an opportunity to influence social care provision, something that was not included in the PPI forum remit. It is intended that LINks will ask local people what they think about local healthcare services, and investigate specific issues of concern to the community. LINks do have powers to hold services to account and get results, ask for information and receive answers in a specified amount of time, and carry out spot-checks to see if services are working well. They can also refer issues to the Overview and Scrutiny Committee. However, a draft policy report on LINks by the Department of Health (2007) confirmed that there are plans for limitations to the areas that LINks members can operate within. The rules on access for PPI forum members were quite extensive but the government believed that a change in the working arrangements was necessary due to significant changes in the health and social care system. LINks members would also appear not to be accountable, except informally to other LINks members and there is no evidence of any intention to provide governance arrangements (Hogg 2007). The accountability arrangements, including the LINks support organisations appears to fall to the Local Authority direct.

LINks organisations are also to be recruited locally and are not intended to have an appointed set membership. The LINks process is based on people being able to choose their level of commitment, in whatever way and time that suits them. This will also mean that there are no pre-set exclusions to membership, which Forums faced, which could be seen as an important change and improvement to policy. The recruitment of the Forum membership was important in this research and given the well-documented problems of recruitment and retention, forum members wanted this developed locally with members keeping the right of appointing their own chairperson. However, LINks groups and panels will also be required to make decisions, set priorities and work on certain subject areas, and these specific membership appointments should be assessed for other competencies following standard recruitment practice, as this continuity was identified in this research as important to success.

The changes to the present structure have been debated within the Local Government and Public Involvement in Health Act (2007). The Act makes further provision to enhance and clarify Section 242 of the NHS Act 2006 and places new duties on NHS Organisations to consult. One of the key difficulties concerns the way that the new Act is likely to limit the capacity of patients and the public to exercise any real influence with local health and social care services.

The arrangements for LINks are meant to be central in expanding patient power and in looking at service user experiences in both health and social care, as a major criticism of Forums was their narrow focus (Baggott 2005, Banks 2001). It is still not completely clear what the government wants from LINks (Hogg 2007), but one benefit is the integration of health and social care and the possibility of further extensions to provide a framework for consultation in other areas of local concern. The boundaries between health, social care, housing or environment are confusing to the public but by taking a wider view of citizen engagement, there could be opportunities to avoid the duplication and overlap experienced by Forums. However, there are some factors that would appear critical to the future success of LINks: its powers, independence and accountability, and whether it really does allow people to be engaged in ways that they want. The terms on which LINks are established and the provision of ongoing funding will also be factors in terms of their stability and public credibility.

The initial paragraph on the future of patient and public involvement indicated concerns around the loss of volunteers, due to changing the formal PPI forum systems. The future of volunteering is clearly a key factor, and a Commission was established in 2006 to recognise the potential of volunteering, and its ability to make a significant contribution towards a more cohesive and effective society (Commission on the Future of Volunteering 2008). In their manifesto for change, the Commission describes the volunteer journey and concludes that there are changes needed in the infrastructure that supports volunteering. Many of these changes need to come from within linked organisations, but they would be greatly helped by sympathetic policies and financial climates set by government. The Commission promotes a clear set of recommendations that improve access, remove obstacles and support employers to modernise the concept of the volunteering infrastructure. These recommendations are underpinned of course, by dedicated funding, to look at alternative rewards and training. Regulatory bodies are also seen as important and would inspect and assess organisations on the support and management of volunteers. There is little doubt that a range of measures are necessary, if we are serious about volunteering being important to local involvement in public services.

Chapter 2 suggested the difficulties inherent in '*engineering democracy*'. Blaug (2002) noted (p.104) that "*it seems to jut out in two directions*", and discussed two competing discourses. First, democracy as decision-making demands a wide distribution of power and scrutiny right. Second, democracy as a civic virtue and way of life requires opportunities to participate, educate and support, in the way that the Commission for Volunteerings vision of volunteering suggests. If PPI forums may have been seen as a means to democratic enrichment, then, from the evidence of this study, the design and implementation of this mechanism has not succeeded in either mode. Blaug (2002), and Lowndes and Wilson (2001) agree in the complexity and risks attached to such designs. "*Because institutional redesign is an embedded and contested process, it is particularly hard for its investigators to control*" (Lowndes and Wilson, 2001, p.643). They argue that the principles of design and redesign of arrangements for public involvement are concerned with the clarity about values that are publicly defensible and legitimate with variability and revisability, rather than a '*one best way*' reflex. However, there is a trade-off, and Lowndes and Wilson (2001) observe that '*imposed*' institutions are often resisted by locals, whilst locally acceptable institutional designs are more likely to '*stick*', but are also less likely to stimulate radical change. Saward (2003) has emphasised the learning that comes from attempts to enact democracy, which need ongoing reflexive debate.

All of these authors raise questions about the importance of having a local involvement process that is adaptable and emphasise that democracy in health will be more effectively promoted by improving decision-making, accountability and transparency and being very honest about the extent and parameters of patient and public involvement rather than pursuing something that is not achievable. If PPI Forums have failed in their short existence to bring significant change, then they may yet serve as a prompt in the future debate about more democratic public services.

7.4 Conclusions

In broadening this research to look at the whole patient and public involvement picture and reflecting back to December 2003 and the PPI forum structure, the question is raised; Are we then back to square one or have the PPI forums moved the NHS on? Is the NHS trapped in a routine of both forgetfulness and re-invention in which professional interests always win out? Alternatively, is this just the latest turn in the pathway, which will lead, albeit very slowly, to a wider acceptance of patient and public voices (Anderson et al 2002). There is also the policy angle and the future implications for patient and public involvement, which are raised within this section.

It is perhaps inevitable that the ceaseless re-organisation of the NHS in almost every sphere has damaged the real development of patient and public involvement work, which clearly needs continuity and stability to prosper (Anderson et al 2002). Any organisation has difficulty in building meaningful relationships if their identity is always changing. The concept of Primary Care Trusts, with unified budgets and with close operational links to primary and community services, meant an opportunity to be in a favourable position to build relationships with patients, the public and local communities, and to gain respect in partnership with others for improving healthcare. However, on the evidence from this research, there are still some gaps between current practice and government expectations.

Many Primary Care Trusts have now increased to much larger and more distant corporate NHS institutions, with huge agendas and some with significant financial problems. In focusing on a variety of literatures and taking the results from this study, it is clear that all relationships should count. This means valuing relationships both internal and external; the formal or the informal; the strategic and the operational; and the institutional and the casual. The necessity remains to bring patients and the public into as many discussions as possible as public involvement is just that: involvement, not just a process for gathering information, which will be considered by another professional (Anderson et al 2002). Relationships could be at the heart of democratic values, and inspire a wider set of values such as partnership and responsibility for common goals. Democratic values are complex and are therefore difficult to nurture within the bureaucracy of the NHS, which is not specifically designed to be democratic, or to promote a culture of openness.

From the results of this research, Forum relationships were still somewhat informal rather than being collaborative and formalised. Direct working relationships between the PPI forums and the Primary Care Trust professionals were variable and there were a number of instances where mistrust and scepticism reigned. There is little doubt also, together with looking at literatures on PPI forums (Baggott 2005), that relationships between PPI forums and their respective constituencies were weak, partly due to little thought being given to their representative function. Of course, it is important to have a range of people with differing skills and competencies but the selection and specification of a range of individuals was missing from the PPI forum recruitment process.

From the literature review in Chapters 2 and 3, there is little doubt that patient and public involvement has been increasingly written into government health policy. However, just because it is policy is not the best reason for pursuing patient and public involvement and doing it because it has to be done is never the best recipe for success and is usually the practice, which simply infuriates people who are invited to participate. There is also no doubt, that as Baggott (2005) argued, the PPI forum structures lacked independence and legitimacy. The government proceeded with a complex framework, which was brought in quickly with little consensus and with little analysis of important issues, for example, the level of involvement. Primary Care Forums were meant to have a range of powers, including levels of inspection and scrutiny, and it will be important for future groups or networks to have a set of powers that allow these fully to address the concerns of the local community.

A survey (Richards and Coulter 2007) for the Picker Institute advised that only 20% of 52 Primary Care Trusts expected patient forums and community groups to influence decision making and few had engaged with people in deciding priorities for commissioning. This research study confirms that although there is some best practice around, there is a big danger that Trusts may, as Picking et al (2001) diagnosed, find innovation and change too difficult. Perhaps part of the reason is that the drivers are too weak and the incentives for good patient and public involvement are not strong enough. If the new Local Government and Public Involvement in Health Act (2007) can make stronger powers available to ensure policy compliance, then Primary Care Trusts may start to address involvement more seriously and substantially.

The question of representativeness and representing others has been a common thread throughout this research. Although some PPI forum members advised that they did represent others, their mechanisms for reporting from and to their respective communities was limited and this questions their abilities to truly represent the views and experiences of others. This could mean that the views expressed were the experiences of their personally known groups, rather than the wider geographical community. There were concerns about PPI forum group abilities to account for and report their successes and failures as annual reports were limited in detail and availability. For future policy and in agreeing with Hogg (2007), accountability and governance should be explicit as the terms of establishment, and funding could be critical for both stability and public credibility.

Few authors, Baggott (2005), Warwick (2007), Hogg (2007), have written specifically on patient and public involvement forums, which is perhaps somewhat surprising given the government emphasis. Work on social movements, volunteering and the predecessors to PPI forums have been considered, but it is also helpful to draw lessons from a comparison between PPI forums and health consumer groups Baggott, Allsop and Jones (2004 and 2005). A difference between the PPI forums and the consumer groups in Allsop, Jones and Baggott's studies was the extent to which consumer groups used extensive networking and both informal and formal policy alliances between them and national consumer organisations. These connections between groups with shared interests makes for a clearly defined national supportive network, which appeared lacking between the majority of PPI forums and between the Forums and their national organisation. Baggott et al do however warn, that the health consumer groups still had relatively little power, unless they are able to mobilise media support.

The government dominates the health policy process and in order to have influence and shape the direction, health related groups like Forums, need to participate in central government processes. Local engagement is still an important means of influencing future policy and developing services. However, as Baggott (2005) determined, groups need to communicate this in a joined up and coherent way, as government policy-makers are more used to receiving documents in a concise manner with clear recommendations. Fundamentally, any future patient and public involvement group or network needs to understand and comply with the rules of the game and be pro active in their policy approach. The media is clearly important by anyone seeking to influence health policy processes and can also have some influence over policy outcomes. Health issues are often newsworthy as they can affect large numbers of the population. In terms of the PPI forum groups and raising their profile, the seeking out of media coverage, whether by newspapers, local television or radio was an essential but missing element, which should be developed in the future. Newsletters and the use of websites and virtual technology are also essential methods of disseminating information, and enabling discussion, consultation and opinion from the local community.

So have Primary Care Patient and Public Involvement Forums lived up to their expectations? These initial expectations were formed from the Statutory Instruments (NHS 2003) and the PPI forum members own expectations for the future. In addition, patient and public expectations are formed from the policy documents advocating patient involvement in individuals own care, expectations from the health care system as a public service and finally concerns about the quality and budget allocation of services (Wait and Nolte 2006). Although it is somewhat easy to say that patient and public involvement forums, like many examples of patient and public involvement initiatives, delivered a more limited amount and have had minimal impact considering their early expectations, they have added to the debate and initiated a different set of strategies. There is also little doubt that if there had been more thought into the concepts and nature of involvement and more dedicated resources, there may well have been different outcomes. There would have been the necessity for change, but possibly this could have been incorporated into current structures without the wholesale need to abolish and start again. The future potential around involvement is still important and the new LINks can use the experiences of the Forums. As indicated earlier in this chapter (page 278), the debates on ladders and continuums raised by other authors (Arnstein 1969, Tritter and McCallum 2006) raise the issue of the amount of power that should be afforded to lay groups. LINks will certainly have to overcome a number of challenges including balancing independence with working in partnership with health organisations, introducing innovative approaches to local community engagement and developing ways of ensuring their roles and activities (around representation) are clear to participants. If effective then everyone stands to gain: lay people, professionals, and organisations and in the longer term, the local community.

In his inaugural speech in June 2007, Gordon Brown emphasised making progress in the NHS by putting more power locally and discussed a new settlement that:
"Is free at the point of need, clear about where the accountability lies, clear where government should set overall principles, clear where it should not interfere, and clear how independently local people should have their voices heard and acted upon in shaping the future of the NHS". It is still unclear exactly what this signifies, but this quote can be

linked back to the government motivations for encouraging patient and public involvement, as highlighted in Chapter 3, but with more emphasis on the effective function. There is little doubt that the NHS is attempting to progress the subject area, as Section 242 of the duty to involve demonstrates (Department of Health 2006), yet a difficult task it remains.

7.5 Dissemination and Future Research

However good your research and no matter how strong the evidence, it will make no difference to policy or practice if it is not communicated to the right people in the right way at the right time. There is, of course, an ethical requirement to ensure that the evidence is disseminated and agreement was reached with potential respondents to feed back the results. At all times this kept the researcher aware of the importance of confidentiality and ensuring that ethical considerations were followed at all times, as described in Chapter 4. The ethical issues do not stop with data collection and analysis; they also extend to the writing and dissemination of the final research.

This transfer of knowledge is something that has been thought about since the start of this study and throughout the lifespan of the research. Obviously, this also links very clearly into personal development but constantly thinking about how this research could add to knowledge on the subject, improved and informed the process. As part of the dissemination process, a number of techniques were considered and completed and these are documented. In addition, the research study was discussed in a variety of sessions involving other members of the DBA programme and staff from the Centre for Health Planning and Management at Keele University. It is also intended to publish part of this study in appropriate journals, particularly as the subject is topical given the governmental changes for patient and public involvement during 2008.

Some examples of research dissemination completed or intended for this study are:

- Kent Primary Care Research Network – University of Greenwich – March 2006 - Presentation of research at one-day regional Kent Primary Care Research conference
- UK Federation of Primary Care Research Organisations Conference – Liverpool – November 27-28th 2006 - Presentation of research study at two-day national conference. The theme for this conference was 'Health and Opportunity' with emphasis on the strength and direction of Primary Care research
- Kent General Practitioners and Registrars - Presentation of research during 2007, plus Kent wide research and development poster presentation
- PPI Forum Group Feedback - Some of the original PPI forum members that participated in the study have left their respective groups but contact details are established and summary versions of the study will be available. The results will be presented formally to any respondents on completion of the thesis

The intention from the outset was to obtain information on the establishment and operation of the Forums, and this research was seen an initial study, from which a further more detailed study could have been generated. Although the fate of the Commission for Patient and Public Involvement in Health was announced quickly, Forums were left with uncertainties about their future until the Expert Panel (2006), finalised the new order.

It is clear that the findings from this research cannot expect to be able of generalisation across all groups regionally or nationally. Nor can the comments be interpreted as a collective view from the case study sites as 50% of the potential group members did not contribute, the same would apply in terms of the Primary Care and other professionals that participated. The picture painted is, however, worth noting as a definite contribution to this ongoing and extensive debate given the somewhat limited quantity of research studies specifically on Primary Care PPI Forum Groups.

The limitations of this research were due mainly to the initial and unexpected difficulties in accessing the PPI forum members and perhaps the limiting of the research to one county. In addition, the initial survey was somewhat limited in its questioning and design, and was ultimately used more to gather information on the profile of the membership rather than giving more extensive answers to the establishment and wider issues of the forum groups. However, the interviews were able to distinguish lines of questioning that developed the questionnaire survey themes enough, to give a more informed insight into the Forums and to give pointers for the future, given the government stance in the subject. All the methodologies provided a base from which other patient and public involvement initiatives could be compared, for example the involvement of users in Local Authority settings, in health consumer groups and of course the current debate in finding a way forward that integrates patient and public involvement in both the NHS health and social care settings. Specifically, there was a missed opportunity in establishing an in-depth, richer data set particularly around the lay experience, their levels of access and scrutiny, and their linkages to volunteering, and these could be areas of interest for further research work. Finally, more in-depth data could have been gathered around the actual Primary Care Trust role and on the actual support from the Forum Support Organisations.

This research raises some questions about the future theoretical base for patient and public involvement studies, just how should future research describe/evaluate PPI arrangements? From this study the interview process and analysis was particularly helpful and produced more insight into the PPI forum groups, perhaps as there was the opportunity to capture individual lay member accounts, which gave a 'rich' data source, together with a schedule of questions that could be repeated for comparison purposes. This highlights the importance, in the future, of considering and establishing more innovative and deliberative methods for accessing information, for example, interactive web sites.

However, this study can now provide a base for further research into the new Local Involvement Networks, which have replaced PPI Forums. What are the specific differences between the two models and how will LINks fair? Future research on patient and public involvement in health and social care will undoubtedly continue to be seen as a desirable practice and will gradually progress, although the precise direction and form may well be contested. PPI forums and now LINks are just the latest turn in the pathway, which will slowly, but ultimately, lead to a wider acceptance of involvement and an acknowledgement to its necessity and importance.

7.5.1 – Final Thoughts – Reflections as the Researcher

Throughout this research, this researcher has drawn on authors who have discussed and drawn parallels and theories on patient and public involvement, including the wider concepts of democracy, representing and relationships in the health context. The research process has also meant the investigation of research and analytical methods. There was a variety of reasons for researching this subject area. In the researcher's professional capacity, there had been an interest in patient and public involvement since 1990, and this interest has continued, although the linkages are now within Primary Care. Theoretically, this research follows on from a previous MSc research dissertation. The subject was patient and public involvement but set within a health promoting hospital setting. Conceptually, the researcher was interested to understand where PPI Forums were located within the broad subject area and of their establishment, operation, activity and ultimately whether they were successful.

The importance of the research ethics processes cannot be underestimated and carrying out this study in a professional and ethical manner was important to the researcher. In the context of this research, which involved a number of respondents, it was important to follow the six key principles of ethical research as specified by the Economic and Social Research Council (ESRC) framework (2006). The University Peer Review and NHS Research Ethical Committee processes and applications took about fifteen months, and the process certainly increased the researcher's personal knowledge and understanding of the requirements at this level of study.

The fieldwork section of the research was particularly rewarding and the forum members, the actors themselves, were clearly a key element in this part of the study. From the researcher's perspective, their openness in answering the questions and willingness to participate and give extra time to the research is valued and their part cannot be underestimated. The participants also added value to the study by commenting and examining the drafts of their respective interviews and ensuring accuracy. The enormity of the analytical task was a surprise, and also the importance of analysing the data to inform policy development and to inform future research priorities was realised and identified. Each part of the analytical process, including the transcription of individual respondent interviews, were completed by the researcher. These processes took considerable time, and the necessity to learn new data software systems was essential, given the quantity of research data generated from the various data collection methods.

While the original aspirations of patient and public involvement (Department of Health 2003) are laudable, local communities knew little about Forums, as they were not high profile, not widely known or advertised and did not command high credibility from their local health organisation. However, the PPI Forum members have certainly enriched and increased the knowledge and understanding in the topic and have given some valuable direction for future development. Members of the new identified LINks system, the early adopter sites, the new proposed host organisations and Local Authorities could benefit from the information in this research, in terms of adding to current knowledge and assisting with effective future patient and public involvement network processes, given the continuing importance in government legislation.

The conclusions from this research are that whatever happens, patient and public involvement in health will only fundamentally prosper if it receives appropriate levels of dedicated funding and if there is understanding of the complexities in the delivery of a '*patient-centred NHS*'. Patient and public involvement will no doubt continue to be a central theme of health policy and therefore it is important to keep a clear perspective on what involvement policies aim to achieve and what health system changes may be needed to allow for their full implementation. There needs to be a professional willingness to embrace change and work on relationships between professional health service organisations and their lay publics, to reach beyond the security of professional power to a more meaningful engagement and to have patient and public involvement initiatives embedded throughout the ethos of all NHS organisations. It is also essential to have institutional forms of collective representation - forums or groups - which clearly demonstrate that they address or represent the health needs of others and for them to identify a repertoire of methods to continually reach individual members of their community. Finally, for all voluntary and statutory organisations to be transparent, to show and be accountable for their results, keeping the community informed of the outcomes and the reasons behind the decision-making.

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APPENDICES

The College Practice

Have PPI Forums lived up to expectations?

Questionnaire Survey (10 questions)

Please tick √ one (or more) box as appropriate. Please use the continuation sheet if you need more space for the answers.

Name:

Forum Group:

1) **Please state your sex?** *Male* ☐ *Female* ☐

2) **To what age group do you belong?** *18-25* ☐ *26-35* ☐ *36-45* ☐ *46-55* ☐ *56-65* ☐ *Over 65* ☐

3) **What is your ethnic group?**

- **Asian/Asian British** *Bangladeshi* ☐ *Pakistani* ☐ *Indian* ☐

Other Asian background (please state……………………………………………………)

- **Black/Black British** *Caribbean* ☐ *African* ☐

Other Black background (please state……………………………………………………)

- **Chinese/Other** *Chinese* ☐

Other ethnic group (please state……………………………………………………)

- **Mixed** *White & Black African* ☐ *White & Black Asian* ☐ *White & Caribbean* ☐
- **White** *British* ☐ *Irish* ☐

4) **How did you first hear about the PPI Forum?**

Advert ☐ *Press* ☐ *TV* ☐ *Leaflet* ☐ *Website* ☐ *Recommendation* ☐

Other ☐ *(please specify…………………………………………………………)*

5) **How were you recruited to the PPI Forum?**

Via Commission for Patient and Public Involvement ☐

Via Forum Support Organisation ☐ *Via the PPI Forum* ☐

Via Personal contact ☐ *Other (please specify……………………………………)*

6) What are your reasons for involvement in the PPI Forums?

- *Past experience or interest in Health Social Care*
  Details ....
- *Interest and want to help in community*
  Details ....
- *Previous background as a volunteer*
  Details..
- *Personal development/Future employment*
  Details..
- *Time available*
  Details..
- *Other reasons*
  (Please state)..

7) Were you a former Community Health Council Member?
Were you a former or are you currently a GP Patient Group member?
Have you been an NHS volunteer before? (please give details)

	Yes	*No*
• *CHC*	☐	☐
• *GP Patient Group*	☐	☐
• *NHS Volunteer*	☐	☐

Details..

8) As a PPI Forum member, do you represent or have a special interest in any particular group or part of the community?

	Yes	*No*
If yes please tick and detail	☐	☐

- *Ethnic group* - *Detail*..
- *Health related group* - *Detail*..
- *Young person group* - *Detail*..
- *Older person group* - *Detail*..
- *Community group* - *Detail*..
- *Disability group* - *Detail*..
- *Other (please specify)* -. *Detail*..

9) What are your expectations for the forum?

Details..

....

10) Would you be prepared to participate in a further interview as part of this research study?

Yes ☐ *No* ☐

Thank you for completing this questionnaire, please return to Marie Gilbert at The College Practice. **<u>Please use the reply-paid envelope provided</u>**

Continuation Sheet

Please use if you need more room for your answers

Question Number

Question Number

Question Number

CONSENT FORM

Study Title: Have patient and public involvement forums lived up to expectations? A qualitative study of Primary Care PPI forum groups

Name of Researcher: Marie Gilbert

Please circle the statements you wish to accept and DELETE those not appropriate:

YES/NO	I agree to take part in the above study (questionnaire/interview)
YES/NO	I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions
YES/NO	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected
YES/NO	I give permission for the interview to be tape recorded
YES/NO	I understand that further consent will be obtained if I agree to the researcher attending and observing a PPI Forum
YES/NO	I understand that further consent will be obtained before use of any anonymised material/quotations in the study

Name of Participant	Date	Signature
Marie Gilbert	Date	Signature

INFORMATION SHEET - Forum Member - Version 2

Study Title: Have patient and public involvement forums lived up to expectations? A qualitative study of Primary Care PPI forum groups

Introduction

You are being invited to take part in this study. Before you decide to take part, it is important for you to understand why the research is being done and what will be involved. Please take time to read the following information carefully and discuss with other people if you wish. Please ask Marie Gilbert if there is anything that is not clear or if you would like more information. Do take time to consider the research and decide whether you are willing to take part.

Purpose of the Study

This research will explore the new Primary Care patient and public involvement forums from their establishment. This study will be new, topical and exploratory and aims to look at the processes of recruitment, reasons for involvement, representing in the community and expectations. Information derived from this study will compare the background of local Primary Care Trust patient forums in Kent and will be a contribution to knowledge and development on the subject.

A number of key research questions arise when considering this research: The study and especially the data gathering process will seek to understand:

- The establishment/profile of the Forums
- The processes by which forum members/FSO's were recruited, plus forum activity and support
- The experiences and expectations of lay members, particularly in regard to recruitment and induction into the Forums
- The issue of PPI forums representing the local community
- Forum relationships with Primary Care Trusts and other organisations

The Duration of the Study

The fieldwork for this research is due to take place from early 2005. The fieldwork process will take approximately six to nine months to complete, based on 1-2 days per week. The study is due to be completed during 2007.

Why you have been chosen

You have been chosen as a participant in this research as you are a forum member. Whether or not you decide to take part is entirely voluntary. If you decide to take part, you will be given this information sheet to keep and you will be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving any reason. If any participant requires assistance with translation or interpretation at any stage of this study, then this will be provided.

What will happen if you take part?

Following your consent, Marie Gilbert will initially send you a questionnaire survey comprising of ten questions with multiple-choice answers. The questions will ask details of personal information on age, background etc so that the structure of the forum can be evaluated. Other questions will be based on reasons for being involved in the PPI Forums, how you were recruited and your views on representing in the community. Participants completing the survey will be asked to indicate their willingness to participate further in the study (individual interview).With approval the interview would be tape recorded so that the researcher can have an accurate record of all the information you provide.

Prior to the interview, any further discussion of the study will be entered into and signed consent to participate will be obtained at that stage. Further consent will be required before use of any anonymised material/quotations in the study. If other methods for data gathering are to be used, e.g. observations at forum meetings then further information will be provided and again consent will be obtained at that time.

What are the anticipated disadvantages and risks of taking part?
There are no anticipated disadvantages or risks to you if you decide to take part in this study. That said, the researcher is asking for 1-2 hours in total of your time. The researcher will ensure the time and the place for the survey and interviews are convenient to you.

What are the possible benefits of taking part?
There are no defined benefits if you take part in this study. However, there will be opportunities to reflect on your own practice and knowledge and to identify practice and knowledge from other forums. A summarised copy of the study will be sent to you on completion, if required.

Confidentiality
All details, which are collected from information you have given during the course of the research, will be kept confidential to the researcher. However, the researcher's two Keele University supervisors, Dr Sarah Derrett and Dr Stephen Cropper will be made aware of the research content but any information used in the study will have your name removed so that you cannot be recognised from it. All data will be kept confidential and will be held securely in a locked cabinet at the College Practice.

Following any interviews, all transcripts will be checked with you for acceptability and accuracy. Any audio tapes used will be kept for two years whilst completing the study and then the tapes will be destroyed. The results will be documented in the study and the whole research study will be presented as a thesis for the Doctorate in Business Administration.

Review
This study proposal has been reviewed at department level by the Centre for Health Planning and Management, Keele University, Staffordshire, and by the University Independent Peer Review Committee. The paper has also been fully reviewed by the NHS Research Ethics Committee process.

Contact Details
Further information can be obtained from Marie Gilbert, Business Director at The College Practice (address below) telephone (01622) 776912.

Please return the enclosed name/address detail sheet plus the questionnaire survey and consent form

The College Practice
50 College Road,
Maidstone,
Kent
ME15 6SB

HAVE PPI FORUMS LIVED UP TO EXPECTATIONS?

Interview Guide for Patient and Public Involvement Forum Members

Objective

- To enlarge and discuss member personal backgrounds (as detailed in questionnaire – objective of establishing similarities/differences). What people make up the membership
- To enlarge on members information on how they were recruited
- To ask members whom they represent within the community they serve. Are they former CHC member/volunteer in health service? Is representing important? Do they understand all the needs of their community? How do they obtain and pass on information?
- To learn about individual member reasons for serving on PPI Forums
- What was the relationship between forums and FSO, CPPIH and PCTs

Type of people involved – Enlarge on questionnaire

- *Ratio of men and women – does you group have a good even spread*
- *Ethnic minorities*
- *Age ranges of the group: under 21; 21-39; 40-60; 60+*
- Have there been changes to the numbers and membership since start of group? If change, are these problematic?

Method of recruitment – Enlarge on questionnaire

- How many members made up the group initially
- How were you recruited?
- *Personal/Advertising*
- *Other group/organisation etc*

Reasons for involvement

- What are your reasons for joining the group? *Time available etc*
- Discuss make-up of group
- The current set-up of the group – how does it operate and run?
- *Is it working, is it correct? If not, why not*

Representing the community

- Whom do you represent?
- *All in community, specific groups/ages. How*
- Does the group try to influence/lobby the organisations for change. *How*
- Are you consulted on all matters? *In what way*
- Does any networking go on between various PPI Forums within Kent?
- Do you contribute directly to the organisations policy decisions?
- *Producing your own ideas/reports. Responding to consultations*
- *How are these disseminated, Are you advised how these are acted upon*

General

- How often does the group meet? *Monthly/quarterly*
- *Do you have admin or other support from the organisation*
- Has the group received training/development opportunities? *What type/all members involved?*
- *How are work plans created/discussed etc*

View/experiences/expectations on the forums

- Now and in the future
- Development of the process
- Networks/contacts and relationships established for future

Other topics raised by respondent

Centre Details/Number: Date:
Patient/Public Identification Number for study: .... **Version 2**

CONSENT FORM

Study Title: Have patient and public involvement forums lived up to expectations? A qualitative study of Primary Care PPI forums groups

Name of Researcher: Marie Gilbert

Please circle the statements you wish to accept and delete those not appropriate:

YES/NO I agree to the researcher attending/observing/tape recording a PPI Forum meeting/session

YES/NO I confirm that I have read/commented/amended transcripts taken at the interview/observation stages

YES/NO I agree that this/these material/quotations can be used in the study

Name of Participant	Date	Signature
Marie Gilbert	Date	Signature

Interview Guide for Commission for Patient and Public in Health personnel

Objectives:

To understand the development of CPPIH
To understand background and development of patient and public involvement within the NHS - Primary Care Trust
To understand how the Forum Support Organisations were recruited
To understand how forum members were recruited
To discuss the exclusion criteria for forum members
To establish the future of CPPIH and PPI Forums future development

Questions to ask and prompts (in italics) to help elicit answers

BACKGROUND AND DEVELOPMENT OF CPPIH

- Background to CPPIH
- Information and detail on the formation of this independent organisation plus the plans for the future (i.e. will forums amalgamate)
- Regional Offices – explain and detail structure i.e. appears large/ complicated etc
- Truly independent?
- The Future?

PUBLIC INVOLVEMENT

- Why is patient and public involvement important?
- Patient & Public – differing meanings?
- Responsibility and working within Primary Care Trusts
- Role of the Forum Support Organisation
- How many Forums do the FSO support and are this number realistic?
- Training and background of FSO's

PPI FORUMS

- Recruitment and exclusion criteria
- Current PPI Forum – perceptions/expectations
- Representing the community – Do the current forums represent the community and local needs, how is this known?
- Are the forums representative of the whole community i.e. ethnic groups, young people etc and is this important
- Numbers – is that right/need more?
- Member on the PCT Board as yet? If not, why not
- Are the forums working - opinion? How? Or what more needs to be done?
- The Future of the forums
- Importance

Other topics raised by respondent

HAVE PPI FORUMS LIVED UP TO EXPECTATIONS

Interview Guide for Primary Care Trust Personnel involved in Patient and Public involvement

Objectives:

To identify the background and development of patient and public involvement within the Primary Care Trust
To obtain perceptions on the PPI Forums – now and for the future
To obtain views on the relationship and development of the PPI Forum process

- What is your PCT approach to PPI?
- Is PPI important within your PCT?
- Does your Trust have a defined policy on PPI?
- What is your role – please describe? Full-time?
- Does the PCT have other staff involved directly with PPI?
- What is your opinion of the current role of the forums? Contacts/networks?
- Do you think the concept of volunteers is correct?
- Can forum members represent their community?
- What is your relationship and how do you work with the a) FSO b) Forum Groups
- Should PCT forums be merged?
- Forum member on PCT Boards?
- What about the future of the forums – any changes etc?

Other topics raised by respondent

HAVE PPI FORUMS LIVED UP TO EXPECTATIONS

Interview Guide for Forum Support Organisation personnel

Objectives:

To understand the development of the Forum Support Organisation
How was the organisation recruited into this role?
The current role of the Forum Support Organisation (training/support etc)
Information on the organisational background and experience

- What is the background to this organisation?
- How many staff members do you have?
- What was the process of recruitment to become an FSO?
- Is the number of forums you represent realistic?
- Presumably, the forums have differing needs, in terms of support.
- What is the FSO support role around these forums, purely administration?
- Does the FSO advise on the direction for the forums to follow?
- Do you think there are any problems associated to the title PPI Forums?
- Forum member recruitment – exclusion criteria
- Do you think the forums represent the community?
- How do members represent the community?
- Do you think there is a possibility that some forums will merge?
- Is your PCT forward thinking regarding PPI?
- What about forums members being on the PCT Board?
- What about the future of the forums?

Other topics raised by respondent

INFORMATION SHEET – ORGANISATIONS

Note: (Same sheet sent to all organisations, amending recipient where appropriate only)

Study Title: Have Patient and Public Involvement Forums lived up to expectations? A qualitative study of Primary Care PPI forum groups

Introduction

You are being invited to take part in this study. Before you decide to take part, it is important for you to understand why the research is being done and what will be involved. Please take time to read the following information carefully and discuss with other people if you wish. Please ask Marie Gilbert if there is anything that is not clear or if you would like more information. Do take time to consider the research and decide whether you are willing to take part.

Purpose of the Study

This research will explore the new Primary Care patient and public involvement forums from their establishment. As you are aware the forums have been a counterpart of NHS, Ambulance and Primary Care Trusts since December 2003 and are supported in administration and training by Forum Support Organisations. This study is important because the patient and public involvement forums are a product of the government's commitment to make sure the NHS delivers patient-centred care. To achieve this aim, the government believes they must involve and consult patients and the public on how health services are planned and developed.

This study will be new, topical and exploratory and aims to look at the processes of recruitment, reasons for involvement, being representative in the community and expectations. Information derived from this study will compare the background of local Primary Care Trust patient forums in Kent and will be a contribution to knowledge and development on the subject.

A number of key research questions arise when considering this research. The study and especially the data gathering process will seek to understand:

- The establishment/profile of the Forums
- The processes by which forum members/FSO's were recruited, plus forum activity and support
- The experiences and expectations of lay members, particularly in regard to recruitment and induction into the Forums
- The issue of PPI forums representing the local community
- Forum relationships with Primary Care Trusts and other organisations

The Duration of the Study

The fieldwork for this research is due to take place in early 2005. The fieldwork process will take approximately six to nine months to complete, based on 1-2 days per week. The study is due to be completed during 2007.

Why you have been chosen

You have been chosen as a participant in this research as you are a *(PCT/CPPIH/FSO)* staff member specifically involved with patient and public involvement. Whether or not you decide to take part is entirely voluntary. If you decide to take part, you will be given this information sheet to keep, and you will be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving any reason. If any participant requires assistance with translation or interpretation at any stage of this study, then this will be provided.

Detail of Observed Meetings (taken from Researcher notes)

Group	Observed Meeting Information
Group A	*The observed session was in May 2006, a morning meeting held within a large medical practice. Only three forum members attended the meeting and in the absence of the Chair, the forum co-ordinator from the Forum Support Organisation chaired the meeting. The meeting was well-organised, well-run and generated good commentary. The meeting went ahead with seven other meeting attendees, these being representatives from the Primary Care Trust and ICAS, three medical practice staff, a local newspaper reporter and a further Forum Support Officer. As the majority of attendees were non-members, it was difficult to make assessments on the group workings or the membership. Previous minutes confirmed other data collected, that this group, in particular, had a repetitive recruitment and retention problem, which limited its progression.*
Group B	*The observational session attended was in July 2006, an evening meeting held at a local community hall. There were five forums members attending, two Forum Support Organisation staff and three other public attendees. The agenda and accompanying papers appeared extensive and thorough and items linked to the findings and activities documented in the annual reports. This group benefited from having a Chair who gave good direction, asked questions but gave good support and informative responses. The meeting was well organised and any letters, or further responses were directed to support staff at the table. The meeting finished after two hours and was kept to time.*
Group D	*The observational session was a morning meeting during July 2006, held in a local community facility. The small audience (2) were advised by forum support staff, that only informal questions could be addressed, as only two forum members attended the meeting. The audience were also advised of ongoing problems of membership and the necessity for future joint working with another neighbouring forum group.*
Group E	*The observational session of this group, was an afternoon meeting in September 2006, held at a local voluntary centre. Eight forum members attended the meeting with two forum support staff, a Primary Care Trust patient group member and three members of the public. No supporting papers were distributed other than to members, but the agenda was structured, although much shorter than other forum groups. From the discussions and the future work plan it was clear that this group had maintained a reasonable number of members but equally kept their programme to areas, which they could cover given their availability and time commitment. This linked with the findings on this forum's activities detailed in the year on year annual reports.*
Group F	*The observational session was an evening meeting during September 2006 at the local council office. Six forum members attended the meeting plus two forum support officers. Other attendees included representatives from the Primary Care Trust, one of which was discussing a specific local health service issue and a member of the Primary Care Trust's own patient group. A number of draft reports were reviewed and it was clear that this group worked with a number of sub groups feeding into the main forum. The details on activities linked to the findings from the annual reports. This group had a popular chair and there was good questioning and debating on all topics, and the meeting kept to time. The detail was thorough and there appeared to be a good working relationship between the group and its Primary Care Trust, with both parties using each other extensively to progress local health matters. There was extensive distribution of reports from the Primary Care Trust, including PALS/complaints information.*
Group H	*The observational session was attended in June 2006, a morning meeting with a group of eleven forum members, (including two new members) and three forum support organisation staff. One of the FSO staff acted as chair for the meeting. There were also seven other attendees, with representation from the Primary Care Trust, community groups and members from the local hospital and ambulance groups. From the start of the meeting, there was notable aggression towards the PCT lead representative, with members requesting definitive answers and there appeared to be a poor working relationship. Many members also appeared to have their own priorities and divisions could be seen at certain points during the meeting. Members also continually used old health service terminology, even with reference to previous local hospital names, which meant it was difficult to follow discussions clearly.*

Data from Survey - Question 9 – What are your expectations for the forum (in full)

		Influence	Patient/ Community Independent Heard & Listened to	Improve Services	Effective Consultation	Understanding NHS Organisations Role	Improved Community Engagement	Positive Impact To health	Retain & Appreciate Forum Members	To Integrate PPI
Group A	M	1								
	F	-	2							
Group B	M	-		1						
	F	-	1		1		1			
Group C	M	-		2			2			
	F	-	1	1		1				
Group D	M	-		1					1	
	F	-	1	1						
Group E	M	-		1						
	F	-		2				1		
Group F	M	-		1		1	1			
	F	1		1					1	
Group G	M	-	2	1						
	F	-		1						1
Group H	M	-		4			1			
	F	-		2						
Totals	**40**	**2**	**7**	**19**	**1**	**2**	**5**	**1**	**2**	**1**