

**A qualitative study of Public Involvement in the
National Cancer Research Network**

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Abstract

Contemporary health policy places increasing emphasis on involving the public in healthcare and health research. This thesis is an empirical investigation of public involvement in the National Cancer Research Network (NCRN) in England, and draws upon emergent themes in the literature relating to quality, epistemic, democratic, accountability and empowerment claims for public involvement in research, as well as Habermas' concepts of system and lifeworld.

Research aims were to explore professional and public accounts of motivations and rationalisations for public involvement in research, consider how public (lifeworld) voices may be integrated into health research (system) spaces and, explore what counts as credible expertise in health research settings. A qualitative approach was adopted and data were collected from selected case studies (a local research panel and national Clinical Studies Groups within the NCRN). The methods included participant and non-participant observations, interviews with group members (professional and public) and documentary analysis.

Analysis of data revealed an inherent ambiguity in relation to public involvement in health research. Involvement served multiple purposes for the public, including the provision of social/support functions and opportunities to reconstruct illness/caring identities, through the development of research skills and active roles within health research. Case studies revealed inherent tensions as the involved public and professionals attempted to demarcate their roles and importantly the foundations of their credibility within the group. The identification of professional and public members' attempts to prevent the integration of the public voice casts doubt on possible empowerment claims. Furthermore, the observation that many public members were highly deferential to certified expertise calls into question their ability to bring a different perspective to research. Ultimately, public involvement in health research may be less the potential to re-couple system and lifeworld but rather a further colonisation of the public lifeworld by professional system knowledge and expertise.

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List of abbreviations used in the thesis

CSGs	Clinical Studies Groups
DeNDRoN	Dementia and Neurodegenerative Disease Network
DH	Department of Health
HSMs	Health Social Movements
HTA	Health Technology Assessment
LINKS	Local Involvement Networks
LRP	Local Research Panel
MHN	Mental Health Network
NCRN	National Cancer Research Network
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
NIHR	National Institute for Health Research
PPI	Patient and Public Involvement
UKCRC	UK Clinical Research Collaboration

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Part One

Chapter One

Introduction to the Study

1.1. Introduction

The purpose of this first chapter is to introduce the aims and scope of the thesis. The chapter will begin by briefly setting the scene for the thesis. Next the aims and objectives of the research will be outlined. Following this, I will provide some background to the study and explain where my interest in the topic originated. Finally, the structure of the thesis and a brief synopsis of each of the chapters will be provided.

1.2. Contextualising the thesis

Contemporary health policy in England increasingly advocates the involvement of patients, carers and members of the public in a variety of ways throughout the National Health Service (NHS) (Florin & Dixon, 2004; Forbat et al, 2009; Harrison, et al, 2002; Hogg, 2007). Patient and public involvement in healthcare spans a wide range of activities in various healthcare settings. For example, within the medical consultation patients are encouraged to express their treatment and healthcare preferences (Thorne et al, 2000) and there is an emphasis on models of 'shared decision-making' between the clinician and the patient (Edwards, 2006). At a more strategic level, the public are increasingly involved in decision-making groups concerning the commissioning of health services (Rowe & Shepherd, 2002). More recently, health policy has placed increasing emphasis on the active involvement of the public in health research decision-making settings (DH, 2006). This thesis specifically addresses public involvement in health research.

The literature highlights various rationales that underpin the development of public involvement in health research. On the one hand, public involvement in areas of healthcare, including health research, has been viewed as a form of deliberative democracy, whereby formerly 'closed' public and private spaces become accessible to lay scrutiny (Barnes, 2008). As part of this

argument, associations are made between public involvement in healthcare and health research as a mechanism to address disparities in power between professionals and the public, with the involvement agenda seen as a way to potentially 'empower' the public (Small & Rhodes, 2000). At another level, public involvement in healthcare and health research can be seen as seeking to restore public trust in expert systems, rendering them more transparent and potentially enhancing expert accountability (Irwin, 2006; Prior, 2003). At a more pragmatic level, public involvement in health research can also be seen as one component within a growing governance framework for research. For example, the recent policy document, '*Best Research for Best Health*' (DH, 2006), emphasises that the public ought to be actively involved in all stages of the research process, from research priority setting exercises through to the dissemination of results. The rationale for public involvement in health research within health policy appears to be primarily based on a quality claim, centred on the practical contribution that the public can make to research (Fudge, et al, 2008). Fundamental to these various overlapping rationales for public involvement in research are considerations of what constitutes as credible expertise and what has been described as the changing relationship between science and society, professionals and the public (Irwin & Michael, 2003).

Yet, despite the various claims for public involvement in health research, there is little empirical evidence that has explored how, or moreover if, the voice of the public is integrated into health research decision-making spaces. Specifically, as Stilgoe et al (2006; 19) ask:

"Are we opening up expertise to new questions and perspectives, or are we just letting people see the experts at work?"

This question provides a starting point for articulating the aims of the thesis. Furthermore, there are very few empirical studies that have considered how members of the public who are involved in research, and professionals working with the public in health research, rationalise involvement. In the light of this, the current thesis sets out to make a contribution to the empirical literature by exploring the context, constructions and dynamics of public involvement in health research. The specific aims and objectives will now be outlined.

1.3. Aims and research questions

The aim of this thesis is to explore public involvement in health research. Specifically, this thesis set out to consider a broad set of research questions:

- How do the 'involved public' and professionals rationalise and account for public involvement in health research?
- What roles do the public play in health research?
- How is the voice of the public integrated into health research spaces?

Furthermore, during data collection and analysis, an additional question emerged:

- What counts as credible expertise in research decision-making groups?

It is important to note that whilst the research questions have been outlined here for the convenience of the reader, they were in fact informed by the literature review that follows in chapter two. In order to explore the questions a qualitative approach to research was taken. Specifically, drawing on the ethnographic tradition, data for this research were collected through interviews, observation (both participant and non-participant) and documentary analysis, conducted with purposively selected case studies from the National Cancer Research Network (NCRN).

1.4. Origins of the study

My approach to this study is reflected in my research questions. I initially came to be interested in the area of public involvement in research following some earlier work on a project concerning researchers' attitudes to public involvement in research. Whilst this was only a small scale study, comprising 15 interviews with university health researchers, the research findings sparked my interest in the area and led me to think about how exactly groups of professionals and the public can work together in a research environment. As part of the 'attitudes' project a second research stage had been devised, based around the construction of a quantitative attitudinal scale that would measure researchers' attitudes towards involving the public

in research. Initially, this scale development was to form the basis of my PhD. However, my own research interests led me in a rather different direction to undertake what is an entirely qualitative piece of work.

The reasons for my decision to change the focus of my PhD are many. Firstly, during my work on the 'attitudes' project I had attended a number of national and international conferences that were designed to showcase examples of how the public had been involved in health and social care research. It was also at this point that I began to engage with the extant health services research literature. I was struck by the increasing number of anecdotal references in the literature, and during conference presentations, made in support of public involvement in research, and a further body of literature that suggested potential difficulties associated with involvement. Furthermore, I was surprised by the ground swell of patients, carers and service users that were attending national conferences and who also expressed a desire to be actively involved in research. However, I was also increasingly aware that there was relatively little research that had actually explored the *process* of involvement and I felt that this was an important area that needed consideration.

I also had some limited experience of involving the public in health services evaluation and audit. Prior to the 'attitudes project' I had worked in a clinical audit department for a Mental Health Trust and was aware of the increasing requirement within the Trust to include lay members as part of the strategic clinical audit meetings (and indeed at other decision-making levels with the Trust). Admittedly, during this time my experience of public involvement was limited to (what I felt was) the seemingly tokenistic involvement of service users who were brought in with limited consideration for what role they might play in the meetings. This appeared to lead to resentment on the part of both the professional staff members and the lay member. Nevertheless, these experiences developed my interest in public involvement as an area of research.

Consequently, my experiences and interests led me to believe that the initial idea to develop an attitudinal scale would not provide the depth and detail that I felt was necessary to understand both the processes of involvement and public and professional attitudes towards involvement. In addition, the scale was proposed to only measure researchers' attitudes, and I was also

interested in hearing the perspectives of members of the public who were involved in research. Secondly, I felt a personal preference towards qualitative research given the emphasis on engaging with research participants and constructing shared understandings. It is for these reasons that the PhD focus changed rather dramatically.

1.5. Public involvement in this study

As this research is concerned with public involvement in research, it seemed both important and appropriate to attempt to involve a lay representative in my own work. Therefore, throughout the course of the research process I have actively involved a lay advisor. The individual selected was suggested to me by my one of my academic supervisors. My lay advisor was considered to be appropriate as he had experience of ill health and engaging with health services and was also involved as a lay member of various research decision-making groups. Throughout the research process, I have met with my lay advisor on a number of occasions. However, much of his involvement has been via emails as his verbal communication and mobility skills are affected by his ill health. My lay advisor has contributed to the research in a number of ways: firstly, during the initial stages of the research, whilst I was refining my ideas, he contributed his own thoughts which helped to shape the direction of the research; he had direct input into the interview questions that were asked; he has commented on draft findings and we have spent a couple of afternoons discussing these findings at length. Throughout the research period, I have maintained a journal of our interactions and discussions in order to reflect on how they may have affected my decisions and shaped the research. I certainly feel that his contribution has been invaluable for adding a further layer of reflection and complexity into the project, alongside my own and the contribution of supervisors.

I will discuss my work with the lay advisor in the methodology and conclusion chapters of this thesis.

1.6. Clarifying terms

In chapter two, I present an overview for my choice of terminology throughout this thesis. However, it is necessary to briefly mention the terms that are used here. The term 'public' has been used within this chapter, the

literature review and within the concluding chapters to refer to patients, carers and users of health services. This term has been chosen as it reflects the current health policy recommendation (Hanley et al, 2004). However, within the empirical data chapters, the term 'consumer' will be used to describe patients, carers and service users, as this is the term that is specifically used within the NCRN. This is discussed in more detail in the next chapter.

'Professional' has been chosen to refer to researchers, scientists and health professionals. Such a distinction between the 'public' and 'professional' is necessary within this research as they describe the roles that these people play in research. The 'professional' describes participants who are involved in health research in a professional capacity, whilst the 'public' take part in research to provide the voice of an individual who has experience of health services or ill health.

1.7. The structure of the thesis

This thesis is divided into three parts and presented in nine chapters. Part one provides the context to the thesis and includes chapters one to four. Part two presents the empirical data and includes chapters five to seven. Part three of the thesis provides a discussion of the findings in relation to the wider literature and theoretical debates. Part three includes chapters eight and nine. A synopsis of each of the chapters will now be provided.

PART ONE

Chapter Two: This chapter provides a review of the topic specific and background literature in order to contextualise the thesis. The review is divided into two sections. Section one describes the policy background and the key claims that are made in support of public involvement in research. Furthermore, it includes a review of the health services research literature specifically concerned with public involvement in research. This covers the areas of health research in which the public are currently involved, the facilitators and barriers to involving the public in research and conceptualisations of public involvement in health research.

Section two reviews the wider political, theoretical and sociological literature that covers issues deemed pertinent to the development, and interpretation of, public involvement in research. This begins with a description of key concepts from the work of Jurgen Habermas that have been used to explore the findings throughout this thesis. The rationale informing the choice of Habermas' work and an outline of the specific concepts that will be used is outlined in section two of the literature review. Following this, the review will cover the political debates concerning democracy, trust and governance in relation to expert systems; the development of grassroots movements in health and the discourse of empowerment, as it relates to public involvement in health research; the evolving relationship between science and society; and the construction of expertise.

Chapter Three: This chapter outlines the research design and methodological approach that was taken in the research. Specifically, the chapter begins by covering my theoretical orientations and methodological considerations and my choice of research methods. Next, it outlines the sampling strategy that was used and provides an account of the research process, including data collection and analysis. As part of this, details of some initial exploratory work will be outlined. The findings from this work informed the main research study and the key findings have been included as an appendix (appendix A). Finally, chapter three will consider issues of rigor in qualitative research and explores the ethical implications of, and my reflections, on the methodological approach taken.

Chapter Four: In this chapter the background and context to each of the case studies is described. This chapter begins by justifying the selection of the National Cancer Research Network as the framework from which the case studies were selected. A narrative considering the nature and purpose of each case study is provided. In addition, an outline of the context in which the observational data were collected, and the scope of the observational, interview and documentary data is provided. Finally, I discuss my own reflections on each of the case studies.

PART TWO

Chapter Five: This is the first of the empirical data chapters. In this chapter the findings concerned with consumer and professional motivations for initial

and continued involvement in health research are considered. This chapter will provide an exploration of the differences between consumer and professional motivations for involvement. This chapter primarily draws on the interview data.

Chapter Six: In this chapter, the practice of public involvement in the case studies is explored. Specifically, this chapter considers how (and if) the voices of the public are integrated into research systems. This chapter primarily draws on the observational data, but with continued reference to the interview data.

Chapter Seven: Building on chapter six, chapter seven is the last of the main empirical data chapters and will explore public and professional constructions of the public claim to credibility in health research. This chapter draws primarily on the interview data.

PART THREE

Chapter Eight: Following the empirical data chapters, chapter eight discusses the findings in relation to each other and the wider literature.

Chapter Nine: This final chapter provides a brief synopsis of the key findings, considers the potential implications that these findings may have for policy and practice and questions that have been raised as a result of this research. Following this, a reflection of some of the methodological considerations and a reflexive account of the research process will be provided. This will include my thoughts on the research process, researching patient and public groups and working with a lay advisor.

Chapter 2

Literature Review

2.1. Introduction

In this chapter I will explore the extant topic specific and the broader contextual literature in order to locate the thesis within the topical, political, theoretical and sociological debates.

Due to the range of subject areas covered within this review, this chapter has been divided into two sections. Section one locates the present research within the topic specific literature. Specifically, section one begins by providing the policy context for public involvement in research. It will then discuss empirical studies concerning public involvement in health services research and will cover the types of health research in which the public are involved, the levels of public involvement in research and proposed facilitators and barriers for public involvement in health research. Following this, section two of the literature review will explore the wider theoretical and sociological debates that are relevant to public involvement in research.

Many of the issues that are covered in this chapter are inevitably interlinked and presenting them in two distinct sections is not straightforward. Therefore, some issues may occasionally be briefly revisited, and references will be made to other parts of the literature review throughout. An iterative approach was taken to this review, with some literature reviewed during the research ideas generation stage, some literature reviewed during data collection, and some reviewed during the analysis and interpretation of the findings.

The literature informing this review was sourced from books, journals (electronic and hand searching through hard copies), policy documents, the grey literature and web-based material. Whilst this review is not a systematic review, the initial literature searches were conducted in a systematic manner, drawing up a list of key search terms related to public involvement

in health research and conducting electronic database searches¹ based on these terms. Following this, the literature review was guided by snowball search methods, for example tracking references and citations, and by scrutinising the emerging research findings.

2.2. Clarification of Terminology

It is necessary to clarify the terms that will be used to describe the different categories of people in this research. Whilst recognising that placing individuals into categories can be rather crude, it is necessary to provide some level of demarcation between people who are involved in research due to their illness experience and people who are involved in research on a professional basis. This will be of particular importance when distinguishing between the roles that individuals' play in health research. However, it is clear that there are some potential problems associated with this and in fact the labelling of individuals involved in research based on their experience of ill health is an issue that will be reflected on in more detail within the discussion chapter.

There is a widespread disagreement amongst medical staff, scientists, researchers, academics and users of healthcare services about the appropriate term to use when referring to individuals who use health services and who are actively involved in research (Beresford, 2007). 'Patients', 'service users', 'users', 'consumers', 'customers', 'clients', 'carers', 'the public', 'stakeholders', 'lay people': these are all terms found within the literature to describe individuals who engage with healthcare services and are involved in research (Boote et al, 2002). The term 'patient' is preferred by some, however for others it is considered to be strongly associated with illness and passivity (Boote et al, 2002) and may not reflect an individual who is active, engaged and able to meaningfully contribute to research. 'Service user' is the most widely used term in the mental health sphere, yet this has been criticised for its association with substance misuse (Boote et al, 2002).

INVOLVE – the organisation established by the Department of Health in order to facilitate involvement in health and social care research – has been active

¹ Electronic databases searched include: IBIS via OVID, Wiley InterScience, CSA Illumina, JSTOR, Medline and CINAHL

in promoting the use of the term 'public'. This is used as a catch-all term and according to the INVOLVE website includes the following people:

"Patients and potential patients; people who use health and social services; informal (unpaid) carers; parents/guardians; disabled people; members of the public who are potential recipients of health promotion programmes, public health programmes, and social service interventions; groups asking for research because they believe they have been exposed to potentially harmful substances or products (e.g. pesticides or asbestos); organisations that represent people who use services."
(INVOLVE, 2008)

This definition is somewhat all encompassing, but despite the detail it appears to neglect 'hard to reach' groups who are rarely involved in research, such as minority ethnic groups and groups who are disadvantaged or socially excluded. The term 'public' may also be disputed due to associations with the general public.

'Consumer' is the preferred term within the cancer research literature and was also the term used by INVOLVE, and within the health services research literature, before it was replaced by 'public'. From an international perspective, 'consumer' is still the term of choice in Australia, in particular within the Cochrane Collaboration (Ward et al, 2009). 'Consumer' typically has connotations of market ideology and public 'choice', and therefore some commentators believe that it is inappropriate (Baggott, 2005; Telford et al 2002).

Whilst recognising the apparent problems in categorising individuals (indeed during my data collection it was clear that participants had very distinct and diverse views about how they would like to be referred to), within this literature review the term 'public' will be used when directly referring to patients, carers or users of healthcare services. This has been selected as it is the term that is centrally promoted. The only exception to this is when specifically referring to individuals who engage with mental health services. In these cases, the preferred term of 'service user' will be used. Similarly, during the findings chapters (which are focussed on the research within the NCRN) the term 'consumer' will be used as this is the term that is used within the NCRN.

In agreement with Oliver et al (2008) the term 'lay' will distinguish between health professionals/researchers and the public. Again, it is recognised that 'lay' is not an acceptable term to everyone, sometimes implying less prestige or worth (Stacey, 1994). However, in the absence of another suitable term 'lay' will be used, but it should be stressed that this is not about making judgements based on worth or competence.

The term 'professional' or 'health professional' has been chosen to define researchers, scientists and health professionals more widely. Again, it is acknowledged that this may create a somewhat false dichotomy between lay and professional, failing to capture the professional backgrounds of many lay people. However, for the purposes of this research and the necessity to distinguish between different groups and their roles in research, 'professional' will be used as it describes the participants who come to research in a professional role. 'The public', on the other hand, take part in research as a patient, carer or health service user representative in order to provide the voice of an individual who has experience of ill health and health services.

2.3 Section One

Introduction

As already outlined, section one of the literature review begins by exploring health policy documents that have provided some of the impetus for the development of public involvement in health research. Following this, the health service research/public health literature concerning public involvement in research will be outlined, including a review of the types of research that the public are involved in, the levels of involvement, and the facilitators and barriers for public involvement in health research.

2.3.1 Public involvement – the policy context

In this section I explore the policy framework and guidance that underpins public involvement in health research. In particular, I consider some of the possible reasons why public involvement in research has emerged within health policy and what claims (implicit or explicit) are made with regards to public involvement in research within the policy literature.

Public involvement in health research has been advocated in England within Department of Health policy documents for a decade (Hanley et al, 2004). The most recent policy document with regard to public involvement in health research is 'Best Research for Best Health' (DH, 2006).

The emergence of the political support for public involvement in health research can be located within wider developments in health policy in England towards involving key stakeholders in healthcare services and decision-making more broadly (Florin & Dixon, 2004). Before critically exploring contemporary policy that specifically addresses public involvement in health research, I first turn to broader health policy developments regarding public involvement in healthcare.

Early influences on public involvement in health research

In England, it has been argued that guidance relating to public involvement in healthcare services and research can be traced back to the 'Griffiths Report' (Boote et al, 2002; DH, 1983) into the role of management in the

National Health Service (NHS). Boote et al (2002) identify an evolving discourse around patient, carer and service user involvement in health care planning, policy and research from this point in the UK. A key recommendation of the Griffiths Report was that the NHS needed to become more responsive to public needs rather than provider interests, signifying a potential change in the relationship between healthcare service providers and healthcare service users (Boote et al, 2002). Tiers of general management were appointed across NHS services, with a remit to identify and meet patient and public preferences for healthcare, and maximise healthcare service user satisfaction (Calnan & Gabe, 2001). Prior to this, there was little consideration of healthcare service users' views or levels of satisfaction (Kelleher et al, 1994). The subsequent 1989 White Paper 'Working for Patients' and the 1990 'NHS and Community Care Act' began to introduce, what some refer to as, 'market principles' into the NHS, and began the development towards an internal market in healthcare (Boote et al, 2002; Rhodes & Nocon, 1998) - establishing a purchaser/provider split in healthcare services. The 1991 'Patient's Charter' outlined a set of patient rights and information about the standards of care that they should expect to receive (Rhodes & Nocon, 1998). In 1992, 'Local Voices' recommended community involvement in the NHS in order to establish priorities and monitor services (Farrell, 2004). This initiative has been criticised for failing to enable public participation in strategic decision-making processes (Rhodes & Nocon, 1998). Furthermore, as part of a choice based agenda there emerged an increasing emphasis on patient satisfaction surveys, coupled with the introduction of clearer patient complaint structures (Shackley & Ryan, 2005). In short, these developments seemed to imply a health service that was open to patient scrutiny and should not be dominated by healthcare provider interests.

It has been argued that such developments began to establish patients and healthcare users as 'consumers' of healthcare, marking out a distinct change in the relationship between healthcare providers and healthcare recipients (Rhodes & Nocon, 1998). Firstly, it is suggested that these policy developments led to a greater emphasis on healthcare provider accountability, with health services increasingly open to public assessment and evaluation (Rhodes & Nocon, 1998). Consumerism, of course, retains connotations of choice. Unlike a paternalist relationship where patients were traditionally framed as grateful and passive recipients of healthcare, under

consumerist rhetoric the patient is technically afforded greater power, treating health care as a commodity – essentially something that can be ‘shopped around for’ (Lupton, 1997a). Freedom to make choices demands that one has some knowledge and understanding of the available health care information (Lupton, 1997a). Arguably, this individualises the philosophy of care by locating the individual as the reflexive, active agent who is (or ought to be) concerned with their own healthcare choices and welfare (Lupton, 1997a; Ward et al, 2009).

Some commentators have suggested that consumerist policy discourse sought a ‘*partial redistribution of power between health professionals and patients*’ (Williamson, 1999a; 150). In this statement, Williamson (1999) is specifically referring to promotion of patients’ interests, with increased patient ‘power’ referring to patient inclusion in the clinical consultation. However, others disagree with Williamson and argue that consumerist ideology has done little towards providing patients and service users with any real power or influence in the policy and health care decision-making process (Gabe et al, 2004; Williams & Calnan, 1991). For example, Williams and Calnan (1991; 716) argue that:

“...emphasis is placed upon GPs achieving quantifiable targets, as well as having to negotiate within internal markets for hospital services. This may lead to the doctor becoming less of an independent professional and more a bureaucratic functionary. Thus, while doctors may be required to become more concerned with meeting consumers’ demands, the actual relationship between themselves and their patients may become more formal and bureaucratic and consequently neglect the crucial aspects of patient satisfaction...”

Other commentators have also argued that the language of patient choice has often been used as a smokescreen to hide a real policy concern with increasing professional accountability and central controls on the health and medical professions (Barnes, 1997a; Calnan & Gabe, 2001; Gustafsson & Driver, 2005; Rhodes & Nocon, 1998; Small & Rhodes, 2000). Furthermore, some commentators have pointed to the correlation between the consumerist approach and ‘fiscal retrenchment’ (Small & Rhodes, 2000; 23), reducing consumerism to little more than public legitimisation of an NHS cost cutting exercise.

Policy developments under the Conservative administration that have been outlined above also marked the beginning of a move towards public involvement in health research (Barnes, 1999b). Through the discourse of consumerism, *'strategies of participation and community involvement'* were outlined to engage with patient and service user preferences (Smith et al, 2008; 303). It is argued that these forms of public involvement in healthcare services and research decision-making were essentially *'top-down and managerially led'* (Smith et al, 2008, 303). In the next section, policy developments in public involvement in health under the New Labour government will be explored.

New Labour, new language?

With New Labour government there appears to be a slight shift in the language of public involvement in healthcare and research, with citizenship included in policy, placing the collective back into the discourse of involvement and participation (Milewa et al, 1999). Newman and Vidler (2006) point to the confused nature of New Labour policy discourse and the so-called *'third way'*. Realigning consumerism with citizenship – the individual and the collective – patient and public *'responsibilities'* as well as *'rights'* featured in the modernisation plan for the NHS. The 1997 White Paper *'The NHS: Modern, Dependable'* (DH, 1997) set out six key principles for the modernisation of the NHS. Most notably amongst these were local responsibility, partnership working and rebuilding public confidence. Gustafsson and Driver (2005; 530) argue that this marked a distinct development away from Conservative emphasis on market based reforms:

"For some Labour modernizers, the journey back to Athens required something different: a deepening of democracy through greater participation in politics and public administration. The Conservative consumer would become a fully fledged citizen, with rights and duties in the governance of the country beyond the voting booth and the marketplace. This notion of the active citizen would be at the core of the government's strategy for 'democratic renewal' and the 'modernization' of public services".

Consequently, a claim for public involvement in health is made based on the democratic renewal of the public sphere. But whilst the 1997 White Paper acknowledged patients and service users as key stakeholders within local health services, it failed to give any indication or guidance on the potential role that they might play, or how participation processes may be evaluated,

leaving some to question the commitment beyond the policy rhetoric (Boote et al, 2002; Gustafsson & Driver, 2005; Rhodes & Nocon, 1998).

Professional accountability also continued to be addressed under New Labour health reforms. 'A First Class Service' (DH, 1999) introduced clinical governance processes into the governing structure of the NHS (Farrell, 2004) and evidence-based medicine became fundamental to clinicians' working lives (Beresford, 2003). Beresford (2003) argues that the development of clinical governance processes, which assess and monitor healthcare service performance against national performance standards, was a response to the Bristol Royal Infirmary Inquiry and the Alder Hay children's hospital scandal. The former was an inquiry following the deaths of 29 babies undergoing heart surgery and highlighted issues regarding poor standards of patient/carer treatment information and secrecy regarding clinicians' performance. The latter concerned the unauthorised use of children's organs, which led to widespread concern regarding professional autonomy and public trust in medical experts (Beresford, 2003). The introduction of clinical governance as a result of these high profile public scandals suggests the following: 1) strengthening professional accountability in order to rebuild public trust in the health service, through the promotion of transparent systems of governance for healthcare; and/or 2) reducing clinical freedom and professional power by exerting central controls and boundaries within which clinicians are required to work.

The Health and Social Care Acts of 2001 and 2003 called for greater public participation in the decision-making processes regarding planning and provision of healthcare services (Tritter & McCallum, 2006). As part of this, most Health Trusts have patient councils with a public 'representative' as part of the Trust board (Boote et al, 2002; Stickley, 2006). Recent developments in public involvement in health and social care in England, under New Labour government, have included the development of an NHS Centre for Involvement (2006), established in order to support the 'embedding' of public involvement in all aspects of the NHS², and the expansion of Local Involvement Networks (LINKs) which promote public involvement in health and social care at a local level (NHS, 2007).

² The NHS Centre for Involvement was subsequently closed in 31st August 2009 following the completion of the Department of Health contract

A further relatively recent programme that may challenge established healthcare service provider/service user relationships is the Expert Patient Programme, which was first referred to in the 1999 White Paper 'Saving Lives: Our Healthier Nation'. The Expert Patient Programme is concerned with developing patients' skills and knowledge in order to empower them to control and more appropriately self-manage their chronic illness, thus claiming to place the emphasis for responsibility back in the hands of the patient (Taylor & Bury, 2007). It follows on the back of a rights agenda and theories of empowerment and active citizenship (Wilson, 2001). However, as will be explored in section 2.4.2, empowerment is a highly contested term. Furthermore, some commentators have questioned the empowering effect of initiatives such as The Expert Patient Programme, suggesting instead that they serve to reinforce the bio-medical paradigm as patients are educated about how to manage their condition based on a dominant professional discourse (Wilson et al, 2007).

In summary, Newman and Vidler (2006; 197) make a useful point that health policy discourse under New Labour government, whilst still using the language of consumerism, also concerns '*new forms of relationships and patterns of identification*'. In particular, they point to the discourse of empowerment coupled with the language of the responsible citizen, alongside the changing nature of expert knowledge and the relationship between expert providers and receivers of health care. In the next section, the implications of such policy discourse will be explored with specific reference to health policy that directly addresses public involvement in health research.

The policy for public involvement in health research

INVOLVE is the central organisation with a remit to encourage and assist researchers to involve patients and carers in health research, and to provide information to patients and carers who want to become involved in research. Established in 1996, as 'Consumers in NHS Research' and renamed as 'INVOLVE' in 2005, the central message promoted by INVOLVE is that public involvement in research is research that is conducted *with* patients rather than *to, about or for* patients (Hanley, 2000).

Public involvement in health research has become increasingly important in health policy over the last decade. One of the earliest policy documents to specifically refer to public involvement in research is 'Patient and Public Involvement in the New NHS' (DH, 1999). This document stated that:

"Research and development (R&D) in the NHS needs to focus on what is important for patients and users. To achieve this patients and service users need to be involved at all stages of the R&D process"
(DH, 1999; 20).

Yet, the rationale informing this directive is unclear, as are the ways in which the public might be involved in the research and development process.

Contemporary policy documents that support the involvement of the public in health research include 'The Research Governance Framework for Health and Social Care' (DH, 2005) and 'Best Research for Best Health' (DH, 2006). The latter states that:

"... patients and the public must be involved in all stages of the research process:

- *Priority setting*
 - *Defining research outcomes*
 - *Selecting research methodology*
 - *Patient recruitment*
 - *Interpretation of findings*
 - *Dissemination of results"*.
- (DH, 2006; 34)

Within 'Best Research for Best Health' the rationale informing the promotion of public involvement in health research appears to be a 'quality' issue, regarding relevance of research to the target population, the reliability of research and uptake of research findings. For example, 'Best Research for Best Health' (DH, 2006; 34) provides a brief rationalisation for public involvement in research:

"We know from our experience that engaging patients and members of the public leads to research that is more relevant to people's needs and concerns, more reliable and more likely to be put into practice".

However, no explicit reference is made to evidence or examples that might substantiate this. Furthermore, noticeably absent from 'The Research Governance Framework for Health and Social Care' (DH, 2005) and 'Best Research for Best Health' (DH, 2006) is a precise definition of what exactly

constitutes public involvement and how the public should be involved in each of the stages that they outline (Fudge et al, 2008).

INVOLVE offer a number of distinct claims concerning the involvement of the public in research:

1. People who use services will be able to offer different perspectives
2. People who use services can help to ensure that issues that are identified and prioritised are important to them and therefore to health care, public health and social care as a whole.
3. Public involvement can help to ensure that money and resources are not wasted on research that has little or no relevance.
4. People who use services can help to ensure that research does not just measure outcomes that are identified and considered important by professionals.
5. People who use services can help with the recruitment of their peers for research projects.
6. People who use services can help access other people who are often marginalised, such as people from black and minority ethnic communities.
7. People who use services can help to disseminate the results of research and work to ensure that changes are implemented.
8. Involvement in research, done well, can help empower people who use services (Hanley et al, 2004).

In the above rationalisation for public involvement in research, offered by INVOLVE, distinct epistemic, quality, accountability and empowerment claims can all be identified. Building on this, in a Department of Health summary of the evidence for public involvement in healthcare, it is stated that:

"The value of patient and public involvement work lies in the exploration of difference, particularly the differences between professional and patient views and between corporate and community views" (Farrell, 2004; 41).

From this, it would appear that an epistemic claim for public involvement is also central to the New Labour health policy. These claims place value on lay experience and knowledge as providing something 'different' from the knowledge and experience of the professionals. Presumably the public bring

a perspective that was previously missing from research decision-making forums? However, in what ways this perspective is different and furthermore how and why it should be incorporated into research is not clear.

I will now turn to summarise the key claims for public involvement in health care service and research that are made within the health policy literature.

Summary of section

This section has provided the policy context for the current research by exploring how public involvement in health research (and more broadly health services) has developed in health policy. The distinct rationalisations informing public involvement in health services and research have been outlined throughout. To summarise, it is apparent that a number of claims for public involvement in health research can be identified from the policy discourse. These are:

1. A quality claim based on the practical contribution that the public are argued to make to the health research process.
2. An epistemic claim based on the 'different perspective' that the public are argued to bring to the health research process.
3. A democratic claim based on opening up research decision-making spaces, which is closely linked to point 4.
4. An accountability claim based on public involvement in research ensuring transparency in, and contributing towards a renewed public trust in, expert decision-making mechanisms.
5. An empowerment claim based on the belief that involving the public in research is empowering for the public.

Having outlined the policy discourse and claims for involvement in research, the literature review will now turn to reflect on the health service research literature that outlines the types of health research that the public have been documented to be involved in and in what ways the public have been involved.

2.3.2 Public involvement in health services research

In the previous section, the policy claims for public involvement in health research were explored. In order to develop this contextualisation, in this section the empirical literature describing the types of research that the public are involved in and the ways in which they are involved will be outlined.

Within the health service research literature there has been a proliferation of examples of active public involvement in research and certainly too many to cover in this literature review. However, it is possible to identify key health research fields within the UK where there appears to be a greater preponderance of reported and documented public involvement in research, such as in mental health, cancer and midwifery and childbirth research. Furthermore, public involvement in research appears to have more of a developed association with the qualitative research tradition and the interpretivist paradigm than with other approaches to research (Thompson et al, 2009). Arguably, this is due to the central focus (within qualitative research) that is given to presenting the voice of the participant. However, there are increasing examples of public involvement in quantitative research, clinical trials and biomedical and laboratory based research (as will be shown).

With regards to the specific fields of health research in which public involvement is most common, although there is not a single comprehensive study that specifically investigates this, two studies identify some key themes. Firstly, Hanley et al (2001) report findings from a survey investigating the extent of public involvement in clinical trials in the UK. The survey was sent to 62 non-pharmaceutical clinical trials offices registered on the National Research Register. The recipients were asked about current public involvement in trials registered with their office and their future intentions with regards to involving the public. Hanley et al (2001) report that perinatal medicine, cardiovascular medicine, HIV/AIDS and cancer research were the main areas where public involvement in clinical trials research was reported. However, they admit that one of the limitations from this study is that the specific nature of the research in which the public are involved is not reported.

Boote et al (2006) conducted a Delphi study into the principles and indicators of successful public involvement in research. The two-round Delphi study comprised a panel of 96 purposively sampled participants, consisting of both members of the public and researchers. As part of this research they asked their panellists to report on the research areas where they had experience of public involvement in research. The most common research areas where public involvement was reported were mental health, physical and learning disabilities, cancer, pregnancy, childbirth and childcare, and older adults. In terms of the types of research that were being conducted in these fields, health services research was the most frequently reported, followed by clinical trials, secondary research, behavioural research and population-based research.

What these two studies, and my reflections on the available literature, highlight is the range of health research topic areas in which the public are involved. The literature indicates examples of public involvement in all aspects of the research process, from research prioritisation through to research dissemination, at both national/strategic and local levels. I will now provide specific examples to illustrate the variety of ways in which the public have been reported to be involved in different health research studies.

Firstly, at a national/strategic level, members of the public are involved in the National Institute for Health and Clinical Excellence (NICE) (Kelson, 2005). NICE is responsible for providing guidelines on health technologies, clinical practice and public health (Kelson, 2005). Topic specific groups comprised of researchers and health professionals work together to produce the guidance. A Patient Involvement Unit (renamed the Patient and Public Involvement Programme in 2005) was established within NICE in 2003 in recognition that:

"Previously, national clinical guidance was usually produced by groups of health professionals and researchers. This approach did not fulfil growing policy requirements to involve patients and carers in healthcare policy, planning and decision-making, and ignored the particular knowledge and expertise offered by patients and carers".
(Kelson, 2005; 304)

It is clear from the statement provided above that the primary rationale for the Patient Involvement Unit within NICE was based on governance requirements, with a secondary epistemic claim for the 'particular knowledge

and expertise' offered by the public. According to Kelson (2005) there appear to be three main areas in which the public are involved in NICE. The first is 'stakeholder consultation', whereby national patient and carer organisations are consulted during the development of specific guidance. It is suggested that these consultation exercises '*might inform the guidance development process*' (Kelson, 2005; 305). This implies that the control of the process and whether to incorporate public perspectives remains the decision of the researchers and health professionals.

The second area in which the public are reported to be involved in NICE is through 'direct input' into the guidance development process. It is claimed that *at least two* members of the public are involved in the topic specific groups, with a remit of contributing a patient/carer perspective to the group discussions (Kelson, 2005) and as such suggests active involvement of the public in the process. However, there does not appear to be any evaluation of these groups, leaving the extent to which the public do *directly* contribute to the NICE guidance open to question.

Lastly, it is suggested that the public are involved in the dissemination of NICE guidance by '*promoting NICE guidance and encouraging its uptake in the NHS at both national and local levels*' (Kelson, 2005). This role does not correspond with the INVOLVE definition of public involvement in research and appears to be more suggestive of the public as recipients, or advocates for research. Therefore, whilst NICE claim to be actively involving the public in their work, without any evaluation of the process, the degree to which this is actually occurring in line with the national policy directive, as provided by INVOLVE, is open to discussion.

One national research organisation that has attempted to evaluate the way that they involve the public is the Health Technology Assessment (HTA) programme (Oliver et al, 2006). The HTA's main remit is to produce independent research and information regarding the effectiveness, costs and impacts of treatments and health technologies (HTA, 2009). As part of this, the programme has endeavoured to involve the public in its work since 1997 (Oliver, et al, 2006). It appears that there are three main areas where the HTA claim to be involving the public. The first is by suggesting a topic for research. This is done by completing an online questionnaire. In their evaluation of this particular role, Oliver et al (2006; 6) concluded:

"Suggestions for research topics from service users face conceptual and procedural barriers not encountered by suggestions from other sources. Nevertheless, service users' suggestions have fed into all three Advisory Panels and, despite their low numbers, have been relatively successful".

Therefore, it would appear that despite the opportunity for patients and carers to provide suggestions for research, based on their experiential perspective, barriers exist regarding these suggestions. However, details are not given on what exactly constitutes the conceptual and procedural barriers.

The second area in which the HTA claim to be involving the public is by serving on a panel of experts assessing and prioritising the suggestions for research. It is stated that there are three expert panels with two members of the public on each panel. However, there is no information on the composition of the panel or the ratio of public to professional members, or how the public are selected and how their voices are integrated. In their evaluation of this role, Oliver et al (2006; 7) found that:

"Discussion of the research topics ... at panel meetings tends to be dominated by research methodology, with few references to patient/public perspectives".

Finally, the third way in which the public are said to be involved in the HTA is by directly commenting on, or peer reviewing, research protocols and assessing these for relevance, applicability and acceptability from a patient/carer perspective. Oliver et al (2006) argue that in this role the public was found to comment on the recruitment processes and the outcomes of the research. However, they conclude that involvement of the public in the peer review process *'generally added little to the Commissioning Board members' judgements about scientific merit'* (Oliver et al, 2006) and suggest that lay reviewers' comments can be sidelined if the Commissioning Board feel that the research is of scientific merit. Consequently, as with public involvement in NICE, the extent to which the public have a voice within the HTA is unclear and open to question.

It is reported that research funding bodies are also increasingly involving public members as part of decision-making and priority setting panels, alongside listing public involvement in research projects as a stipulation for funding (Beresford, 2007; O'Donnell & Entwistle, 2004a). For example, the UK National Institute for Health Research claim that structures are being

developed to support public involvement throughout the organisation in a variety of ways, including research priority setting and peer reviewing applications for research funding (NIHR, 2009). However, as this is a relatively recent development as of yet there is no documented evaluation of the process.

In addition to the reported role of the public in research priority setting in national organisations, there is research detailing this activity in specific studies. For example, Wright et al (2007) report on the 'Macmillan Listening Study', where 17 focus groups were conducted with 105 cancer patients to share their views and priorities for cancer research. Wright et al (2007; S3) report 'key differences' between the priorities of the patient groups compared to those of the professional group:

"Research prioritization studies involving health care professionals often identify the design and co-ordination of research, research into the biological effects of treatment, symptom management, and service delivery and organisational issues as areas of high priority. These were not reflected in the top priority areas of the Macmillan Listening Study. Conversely, priorities identified by the Study participants, such as research into self-management activities and the impact of cancer on day-to-day lives, are not commonly determined by health care professionals".

At one level, these findings appear to support the epistemic claim for involvement, highlighting the 'different viewpoint' that the public can bring to research. However, how the difference between patient and professional priorities might be addressed and resolved is not discussed by Wright et al (2007). In a similar study, Tallon et al (2000) consulted patients and professionals concerning research priorities in relation to osteoarthritis. As with Wright et al (2007), Tallon et al (2000) noted a *clear mismatch* between the current research agenda and the priorities of patients and carers. More specifically:

"All the clinicians felt that drug therapies, especially non-steroidal anti-inflammatory drugs were over-researched. Rheumatologists thought more research was needed on appropriate indications for knee replacement and that better outcome measures should be developed. Physiotherapists felt that little research had addressed clinically relevant questions and they were particularly concerned about the absence of research into exercise based therapies. GPs highlighted difficulties in finding good evidence about the success rates of surgical procedures and wanted more research on conservative treatments such as exercise and education. Patients

were also interested in knowing more about the effectiveness of conservative therapies and of self-help and coping strategies".
(Buckley et al, 2007; 76)

What this indicates is not just the 'different perspective' of the public in relation to professionals, but also the different perspectives and research priorities between professional groups.

In terms of public involvement in developing research bids, Staniszewska et al (2007) report on the development of a research bid for a project that explored parents' experiences of giving birth to pre-term babies. The researchers worked with a group of parents with experience of pre-term babies to develop the research questions, aims and methods. Staniszewska et al (2007) report that the focus of the research was directed by the parents' perspectives. The researchers argue that involving the public in the initial stages led to a research bid that:

"...is more firmly rooted in the reality of parental experience, has more relevant research questions, uses appropriate and sensitive methods and has a strong dissemination strategy to reach out to health-care professionals."
(Staniszewska et al, 2007; 179)

A number of the policy claims are implicit within the above statement, including the epistemic claim and quality-based claims for involving the public in research.

In the study discussed above, the role that the parents involved in developing the bid played in the actual research process was not documented. However, there are some examples in the literature where the public are reported to have been involved throughout the research process from the initial design stage of a research project through to the project dissemination. For example, Ross et al (2005) describe the involvement of older people in a project that explored older people's needs and expectations regarding information on falls. The researchers used a participatory research model. The researchers developed a public panel, comprised of older adult participants. The public panel were reported to be involved in the project management, working with the researchers from initiation through to the final dissemination stages of the research. The authors report on several aspects where they felt that the public panel had enhanced the quality of the

research, including contributing to the development of the interview agenda and undertaking some preliminary interview analysis, which was argued to have '*add[ed] another layer of insight to interpretation of the data*' (Ross et al, 2005; 274). However, whilst the authors do not report on what distinguished this additional layer of insight and interpretation from their own, it appears that as with Staniszewska et al (2007), they are making epistemic and quality based claims for involving the public in research.

Whilst the above studies claim a value for public involvement based on epistemic, quality and democratic claims, a study by Koops and Lindley (2002) highlights the potential role for the public in confirming the acceptability of research. Koops and Lindley (2002) involved the public in order to address a specific problem with the premature closure of pharmaceutical trials for stroke patients, due to their association with 'high risk factors' for patients taking part in them. Koops and Lindley (2002) conducted consultation exercises with stroke patients to address the ethical implications of the trials and to ascertain what stroke patients would find ethically acceptable. As a result of the consultation exercises, Koops and Lindley (2002) argue that they adjusted their patient information sheets in order to make the trial more 'ethically acceptable' to patients. They state that the research was granted research ethics approval with only one cycle of minimal amendments. In this study, Koops and Lindley (2002) appear to establish a distinct role for the public in providing ethical evaluations of research, based on their personal experience. This was argued to be vital in ensuring that the study was granted ethical approval with only minor amendments.

Summary of section

To summarise, in this section specific examples of public involvement in research have been explored. In particular, examples of public involvement at national and local levels indicate that the public are involved in research in a variety of ways. At a national level, public involvement is seemingly recognised as a governance requirement, with quality, epistemic and democratic based claims found within organisations' rationalisations for public involvement in research. However, whilst structures for public involvement in research prioritisation exercises and the peer reviewing of research protocols appeared to be in place, it would seem that the extent to

which the public actually have an impact within these organisations is unclear.

Away from the large national organisations, there were examples of the public contributing to research. It was illustrated how these examples appear to be primarily based on the 'different perspective' of the public, suggesting strong variation in public and professional research priorities. Consequently, as research conducted within the NHS is primarily funded through general taxation, it seems that a clear democratic claim for involvement can be made.

Having so far explored some practical examples of public involvement in research, the literature review will now turn to reflect on arguments that are presented for involving the public in research.

2.3.3. Reasons to involve the public in health research

There are numerous arguments proposed for involving the public in research cited in the health services research literature. The arguments tend to fall into two, although not exclusive categories; those based on moral and political principles and consequentialist based arguments (Thompson et al, 2009). The moral and political arguments for involving the public in research centre on concepts of rights, citizenship and democracy. In contrast, the consequentialist arguments focus on the actual contribution of the public to research and its wider acceptability (Thompson et al, 2009). A different classification is provided by Stirling (2005) who describes normative, instrumental and substantive arguments for involvement. Normative arguments are based on public involvement being 'the right thing to do' and like the moral and political category suggested by Thompson et al (2009) are concerned with involvement as a democratic right and based on concepts of equality and social justice. Instrumental arguments frame involvement as a mechanism to better achieve strategic aims (for example building public trust in science), whilst substantive arguments are concerned with the contribution of the public to the quality of research. Instrumental and substantive arguments are similar to the consequentialist category proposed by Thompson et al (2009).

The most commonly cited argument based on moral and political principles is that as citizens and taxpayers, individuals have a democratic right to influence research that is publicly funded (Dyer, 2004; Dutton, 1984; O'Donnell & Entwistle, 2004b; Thompson et al, 2009). This includes NHS research and research that is conducted or funded by charitable organisations and medical research charities, as public donations comprise a large part of the finance for these organisations (Kent, 2002).

In terms of the consequentialist based arguments for involvement, from the literature it is possible to identify a number of practical benefits that are said to result from involving the public in research. Firstly, public involvement in research is said to increase the relevance, credibility and acceptability of research (Entwistle et al 1998; Oliver, 1995; Paterson, 2004; Tallon & Dieppe, 2000). For example, in the previous section the study by Koops and Linley (2002) highlighted the role of the public in assessing the acceptability of a research project.

Secondly, it is argued that the public bring a unique contribution to research in terms of their personal knowledge of a particular illness or condition or their experiences of services, or their 'experiential expertise' (Caron-Flinterman, 2005; Faulkner & Thomas, 2002). It is suggested that this 'alternative perspective' can provide an element of 'reality check' - reminding researchers of the overall purpose of their work as the ultimate recipients of the research (Rhodes et al 2002; Paterson, 2004).

As part of the 'different perspective' argument, it is claimed that public involvement in research can improve the overall quality of research by expanding its capacity to include issues that have been prioritised by the end users of research - issues that researchers may have been unaware of (Boote et al, 2006; Entwistle et al 1998; Hanley, 2000; Herxheimer, 1997; Telford et al 2002). Examples of this were highlighted in the previous section. At a more practical level, public involvement in research is argued to be beneficial for recruitment to trials or research studies, with public members often successfully engaging potential participants or suggesting different approaches that researchers may use in order to successfully recruit participants (Boote et al, 2006; Hanley et al. 2004).

Furthermore it is suggested that the public can help to maintain a focus on the outcomes of a research project. Some commentators have argued that the public can assist with research dissemination and often push for change as a result of a project (Hanley 2000). It is suggested that this helps to ensure that any recommendations and changes are implemented and followed up (Hanley, 2000; Telford et al, 2002). Accordingly, it would appear that the public play the role of an 'auditor', or 'watchdog' in research.

Lastly, in addition to the practical aspects, some consequentialist based arguments consider the impact of involvement in terms of the wider societal acceptance of research. For example, increased accountability amongst the research group is cited as a potential benefit of public involvement (O'Donnell & Entwistle, 2004b). It is argued that researchers are required to work much more transparently in order for the public to understand the research process (O'Donnell & Entwistle, 2004b). More transparent working practices are said to increase wider public trust in research (Stilgoe et al, 2006). Some researchers have reported public involvement in research as a mechanism for legitimising research aims, methods and findings (Thompson et al, 2009). As part of this argument it has been reported that having the public on board with a research project can be a validating experience for researchers, with some researchers associating this validation with a sense of increased public respect for the research (Thompson et al 2009). Furthermore, O'Donnell and Entwistle (2004b) argue that public involvement during the early research prioritisation and review stages increases public confidence that research funding is being allocated fairly and by a committee that is not restricted to the views of a dominant professional elite.

This section has outlined the primary arguments for public involvement found within the health service literature. The next section briefly turns to the literature concerning public motivations for involvement in research.

2.3.4. Public motivations for involvement in health research

There appears to be a dearth of literature concerning public motivations for becoming involved in research. Within this limited literature, the motivations for the public to become involved in research include both motivations for societal benefit and motivations based on personal benefit. For example, altruistic motivations, based on an individual's desire to 'leave a legacy and

influence research for the benefit of others' (Tarpey, 2006; 14) and motivations based on an individual's desire to change services and create more patient-centred services (Staniszewska et al, 2007) reflect views of involvement in research driven by a wish to impact on the wider society.

On the other hand, personal benefits associated with involvement in research include the opportunity for individuals to turn a bad situation into something good, i.e. use their experiences of ill health in a more positive and constructive manner (Paterson, 2004), having renewed interests and the opportunities to develop new skills and knowledge (Paterson, 2004; Staley, 2009) and the development of new social opportunities, by meeting people through research groups (Paterson, 2004).

Having so far explored the arguments for public involvement in research, and the potential benefits for lay people who are involved in research, this review will now turn to consider the barriers to public involvement in health research.

2.3.5. Barriers to public involvement in health research

The barriers to public involvement in research are well documented in the health services research literature. Interestingly, some of the barriers to involvement provide a direct contrast with the arguments suggested for involving the public in research. Four areas can be identified; epistemic barriers, quality barriers, practicality barriers and barriers based around professional knowledge and understanding.

Firstly, in terms of the epistemic barriers for involvement, lay participants' 'lack of specialist skills' or their inability to converse fluently in research language and jargon is reported as a potential problem that can hinder effective involvement and communication (Oliver et al, 2001). These arguments appear to stand in contrast to the emphasis that is given to the 'different perspective' that the public bring to research.

Mismatches in the views, values and priorities of researchers and members of the public are often referred to anecdotally and have been suggested as a potential difficulty when involving the public in research (Grant-Pearce et al, 1998). Again, as part of the 'different perspective' argument for involvement,

the wide variety of viewpoints is often stated as one of the fundamental benefits for involving the public in research. By suggesting the possibility of disagreement between the public and professionals as a potential barrier, the epistemic claim for involvement is undermined.

Secondly, Caron-Flinterman et al (2005a) argue that a fundamental concern within the research community is the possibility for public involvement to undermine the quality of clinical research. This argument was based on both lay participants inability to understand or converse in the scientific language, namely the epistemic argument as discussed above – and also lay participants' inability to consider long-term research aims, or to consider research topics other than those based on social issues as a priority.

Thirdly, in terms of the practical barriers, resource allocation issues and the cost of public involvement, both in time and monetary value, are cited as key concerns and barriers to involvement (Baxter et al, 2001; Boote et al. 2002; O'Donnell & Entwistle, 2004b). This may suggest that whilst there is clear support for public involvement in the government health policy, in reality the structures are not sufficient to facilitate this.

Finally, Boote et al (2002) suggest that there is a lack of understanding amongst the research community concerning who to involve in research, how to recruit them and concerns regarding the representativeness of lay members of research groups. Indeed, how to obtain a representative sample of public members in a research project and whether one public member can represent the views of the community reportedly surface as barriers (Boote et al, 2002; O'Donnell & Entwistle, 2004a, 2004b). However, Beresford (2007) argues that issues of diversity in involvement are often confused with issues of representativeness. Beresford (2007) argues that achieving a representative sample of public members within a research project is an unlikely and unnecessary approach.

It has been reported that some professionals can be unresponsive to public involvement in research due to the potential relinquishing of 'power' and the authority that is associated with this (Florin & Dixon, 2004; Johnson & Silburn, 2000; Nathan et al, 2006). For example, Dutton (1984; 170) argues that some scientists view public involvement as a '*harmful intrusion of inexpert and alarmist ideas*'. Building on this argument, Tyrer (2002; 406)

makes an interesting comment that is indicative of some professional resistance to involvement:

"There is a real danger that the engine of user initiatives in mental health services, although positive in principle, will accelerate out of control and drive mental health research into the sand."

This argument frames the public perspective as 'out of control', clearly viewing a divide between the role and place of experts and the roles and place of non-experts. Ward et al (2009) suggest that these arguments may be regarded as a form of 'professionalising strategy', whereby researchers' actively seek to protect the boundaries of their profession by maintaining the exclusive and esoteric nature of research.

The previous three sections have provided the key arguments presented for and against public involvement in research. It has been highlighted how some of these arguments overlap, with the 'different perspective' of the public presented as both a rationale for involvement and a barrier to involvement. Furthermore, it appears that whilst some commentators and the policy documents suggest public involvement has contributed towards improved quality in research, others are concerned that involvement will have a detrimental effect on the research process and outputs. Consequently, the previous sections have illustrated that whilst public involvement in research is presented in the health policy as a simple policy statement, the arguments presented for and against public involvement in research illustrate the highly complex and ambiguous nature of this policy directive.

In the next section, the literature review will reflect on a further aspect of public involvement in research that has led to theoretical debate, which is the conceptualisation of 'levels of public involvement in research'.

2.3.6. Conceptualising the levels of public involvement in research

Having so far explored the arguments presented for and against public involvement in research, this section will examine the different approaches that have been taken to conceptualising levels of involvement. These arguments are important because the various conceptualisations appear to be associated with the degree of power, or empowerment of the involved

public. Therefore, consideration of these arguments is necessary given the policy claim that public involvement in research can be empowering for the public.

A number of commentators have reflected on the different approaches to public involvement in research as constituting a hierarchy. As part of this a number of models and frameworks for participation have been adopted, and/or adapted, from other areas of research. For example, Arnstein's (1969) ladder of citizen engagement is one of the most commonly cited models (see figure 2.1). This model is based on eight possible 'rungs' of a participation ladder. The bottom rungs are not considered to constitute involvement, the central rungs are often regarded as tokenistic attempts to involve the public, whilst the top rungs are concerned with a redistribution of power (Tritter & McCallum, 2006).

An alternative model has been suggested by Hoyes et al (1993) for use within the research decision-making process (see figure 2.2). Hoyes et al (1993) suggest six levels of participation in decisions, with level 1 being the highest (most desirable) and level 6 being the lowest (least desirable).

Figure 2.1: Arnstein's (1969) ladder of citizen engagement

8. Citizen control
7. Delegated power
6. Partnership
5. Placation
4. Consultation
3. Informing
2. Therapy
1. Manipulation

Figure 2.2: Hoyes et al (1993) model of public participation in decision-making

1. Users have the authority to take decisions
2. Users have the authority to take selected decisions
3. Users' views are sought before decisions are finalised
4. Users may take the initiative to influence decisions
5. Decisions are publicised and explained before implementation
6. Information is given about decisions made

Within the health services research literature, and particularly that produced by INVOLVE, three hierarchical levels of public involvement in research are commonly identified: Consultation (at the bottom of the hierarchy); collaboration; and user led research (at the top of the hierarchy) (Hanley et al 2000). Consultation is sometimes regarded as a tokenistic gesture because the research aims and methods are usually predetermined by the professional researcher (Smith et al, 2008). Collaboration implies more of a joint venture, or a partnership, between the public and researchers. Whilst user led research is research that is determined, planned and conducted by the public, sometimes with the assistance of a professional researcher. User led, or user controlled (Turner & Beresford, 2005) research indicates a greater degree of public influence and control in the research process and is sometimes hailed as the 'gold standard' in public involvement in research (Tritter & McCallum, 2006).

What is apparent from these models of involvement is the clear focus on the distribution of power and control within the research process. For example, lower levels of involvement are generally about a one-way transfer of information, signifying a lesser degree of control and are often considered as poor attempts at involvement. Higher levels of involvement become increasingly concerned with a dialogue between the public and professionals (Rowe & Frewer, 2000) and are often viewed as preferential (Tritter & McCallum, 2006). Beresford (2002) regards consultation and collaboration as part of the consumerist ideology and believes consultation and collaboration are primarily concerned with bringing about an impact on services with public involvement conducted as part of service improvement.

Models of public involvement are a useful benchmarking tool. However, as Tritter and McCallum (2006; 162) suggest a linear model of involvement is not appropriate for application to public involvement as such models *"conflate means and ends, implying that user empowerment should be the sole aim."* As also noted by Smith et al (2008), hierarchical structures often fail to capture the dynamic nature of public involvement. It can be misleading to place citizen control as the highest 'rung', and thereby most desirable form of involvement, as this implies that public control is the ultimate aim of involvement in research when in actuality the aims and motivating factors for involvement are much more varied (Tritter & McCallum, 2006; Smith et al, 2008).

Furthermore, hierarchical models for evaluating public involvement in research potentially elevate the process of involvement over the research outcome. For example, a consultation exercise might result in a better outcome than a research project conducted in partnership. However, using a hierarchical model, such as Arnstein's (1969) ladder, the consultation exercise would be classed as tokenism. Rather than holding citizen control as the ultimate level of participation, Tritter and McCallum (2006) argue that the level of involvement should fit the needs of the research project, along with the needs and desires of all members of the research team, including the public members. However, for some discourses of involvement that have developed out of a challenge to medical practice (for example, in mental health research (Telford & Faulkner, 2004) such a suggestion may not be considered appropriate. Therefore, whilst it is certainly appropriate to highlight the complexity of public involvement in research and the limitations of hierarchical models, the power dynamics between the public and professionals involved in research processes must also be considered. This will be explored in more detail in section 2.4.2 (*The relationship between science & society*).

One possible way to address the variation in approaches to public involvement has been provided by Telford et al (2004), in their 'principles and indicators of successful public involvement in NHS research'. Telford et al (2004; 216) provide eight guiding principles for public involvement.

These include:

1. The roles of the public are agreed between the researchers and the public involved in the research.
2. Researchers budget appropriately for the costs of public involvement in research.
3. Researchers respect the differing skills, knowledge and experience of the public.
4. The public are offered training and personal support, to enable them to be involved in research.
5. Researchers ensure that they have the necessary skills to involve the public in the research process.
6. The public are involved in decisions about how participants are both recruited and kept informed about the progress of the research.
7. Public involvement is described in research reports.

8. Research findings are available to the public, in formats and in a language they can easily understand.

However, Telford et al (2002) and Boote et al (2006) acknowledge that further research is needed in order to fully understand the usefulness and impact of implementing these principles in practice.

This section has outlined some of the key arguments and problems concerned with conceptualising levels of public involvement in research. What these conceptualisations add to the debate is a contribution to an overall picture of public involvement in health research as complex and ambiguous. The next section will build on this point by providing a summary of the arguments presented in section one of the literature review.

2.3.7. Summary of section one

In section one of this review, the literature pertaining to public involvement in health research has been explored. The section began by outlining the policy for public involvement in research and exploring examples of public involvement in health research, including the proposed benefits and barriers associated with involvement. It was suggested that public involvement in health research is based on a number of claims. These include:

1. **A quality claim** - based on the practical contribution that the public are said to make to health research.
2. **An epistemic claim** – based on the ‘different perspective’ that the public are argued to bring to the health research process.
3. **A democratic claim** – based on opening up decision-making spaces.
4. **An accountability claim** – based on public involvement ensuring transparency and accountability in expert systems.
5. **An empowerment claim** – based on a belief that involvement in research can address unequal distribution of power between service users and service providers.

Conceptual frameworks for public involvement were explored, including the widely cited ‘ladder of involvement’ (Arstein, 1969). These suggest different associations between involvement and increased power. However, it is clear that such models do not capture the complex and ambiguous nature of public

involvement in health research. As a result of the complexities associated with public involvement in research, in section two of the literature review the sociological literature will be considered. It is suggested that public involvement in research is a micro example of wider macro debates, and as such section two will explore some of these key theoretical debates in order to provide further context to the research questions.

2.4 Section Two

Introduction to section

Public involvement in health research can be seen as a micro example of wider macro theoretical debates. It forms part of a number of developments in the broad field of science and society, or what Leach et al (2005; 3) refer to as '*...complex interfaces and intersections between science and citizenship...*'. These include: political debates concerning democracy, trust and governance; the development of grassroots movements in health and the discourse of empowerment; the evolving relationship between science and society; and the construction of expertise. As such, exploration of these interrelated fields is necessary in order to form a broader understanding of the theoretical context informing the development of public involvement in health research.

This section of the literature review will explore these debates. As a starting point, the review will begin by outlining some of the key arguments provided by Habermas, in his critical theory of society. In accordance with the rationalisation provided by Britten (2008; 18) a focus on Habermas' social theory has been chosen as his work provides "*... a means for linking macro and micro levels of society while also enabling a detailed analysis of lay perspectives*". Moreover, a number of sociologists of health and illness have recently drawn on the work of Habermas in exploring the emergence of 'lay health knowledge' (Williams & Popay, 2001), 'doctor/patient interaction' (Mishler, 1984; Scambler & Britten, 2003) and the emergence of forms of patient action in health care (Kelleher, 2001). Consequently, key elements of Habermas' work have been usefully applied in this field. Of particular concern to my research are Habermas' ideas about:

"...the deformation of the public sphere under conditions of advanced capitalism, for example; his critique of the way in which political decisions are re-defined as technical prescriptions; his perspective on the dominance of technique over praxis; and his arguments about the colonization of the lifeworld – in both public and private spheres – by the powers of the state and the forces of capitalism; and the possibilities of resistance with both politics and civil society".
(Williams & Popay, 2001; 29)

I will now turn to explore these ideas in more detail and their utility to my research questions.

2.4.1. Habermas' critical theory of society

At this point it is important to outline key ideas from Habermas' grand theory of society. As already stated, Habermas provides some key theoretical ideas that are relevant to many of the debates concerning public involvement in research. His ideas will be referred to throughout the proceeding sections of this review and the thesis as a whole. In the proceeding sections Habermas' ideas on the 'system' and the 'life-world', the rise of New Social Movements and deliberative democracy will be explored. As explained above, these theories are particularly pertinent as they highlight the interface between science and society. As with Williams and Popay (2001), it is my intention that drawing on Habermas' work will be useful in exploring my empirical research and the wider contextual literature, rather than provide a distinct critical contribution to his ideas. I will first turn to the concepts of 'system' and 'life-world'.

System and life-world

In his grand theory of social life, Habermas (1987) provides a useful distinction between lay forms of knowledge and certified forms of knowledge. Broadly drawing on a Marxist division of society, Habermas (1987) distinguishes between two spheres of social life: the system and the life-world (Barry et al, 2001; Britten, 2008; Finlayson, 2005; Jones, 2003). Building on Weber's theory of rationalism³, Habermas identified a different form of rationality in each of these two spheres (Scambler, 1987). The system is governed by instrumental rationality – orientated towards successful outputs, whilst the life-world is governed by communicative rationality – orientated towards reasoning and achieving mutual understanding (Jones, 2003; Scambler, 1987).

Essentially, the life-world refers to the sphere of social life whereby knowledge and understanding are culturally reproduced (Britten, 2008; Habermas, 1987). Culture, traditions, basic assumptions and common sense understandings are all rooted within the life-world (Cuff et al, 2006). Within the life-world, individuals come to understand themselves and their social surroundings through what Habermas calls 'communicative rationality',

³ Weber painted a bleak picture of contemporary society whereby instrumental rationality, e.g. the pursuit of technical efficiency, dominated and as such the pursuit of meaning was increasingly lost. Weber felt that this progression was not only inevitable but also irreversible (Jones, 2003).

based on goals orientated towards sharing and constructing common understanding (Barry et al, 2001). As Habermas (1987; 138) states:

"The interactions woven into the fabric of everyday communicative practice constitute the medium through which culture, society and person get reproduced. These reproduction processes cover the symbolic structures of the lifeworld."

Finlayson (2005; 51) goes further to suggest that the life-world is:

"...the informal and unmarketized domains of social life: family and the household, culture, political life outside of organised parties, mass media, voluntary organizations, and so on."

In the field of health, the voice of the life-world is used to refer to the patient's contextually grounded knowledge and understandings of self (Barry et al, 2001) - in other words their 'experiential expertise'. Experiential expertise will be explored in more depth in section 2.4.6.

On the other hand, the 'system' refers to areas of social life that are concerned with the material reproduction of society via instrumental and strategic rationality, i.e. goals orientated towards achieving successful actions and outputs (Britten, 2008; Finlayson, 2005). For example, the economy and the state are 'systems' sites orientated towards material reproduction. Scambler (1987) points to 'formal knowledge' - the knowledge of professional experts - as constituting systems rationality. In the context of health and medicine, Mishler (1984) made a direct link between the 'voice of medicine' and the 'system'. Consequently, it could be argued that health researchers working within the technical discourse of science and medicine can be identified as part of the system.

One of the central arguments articulated by Habermas (1987) is that there has been a separation of the system and the life-world in modern societies. Habermas (1987) argues that this has led to the increasing systematisation of areas of the life-world, or the gradual reshaping of the life-world in systems terms (Cuff et al, 2006). Habermas (1987) labels this process as 'the colonisation of the life-world' (Braaten, 1991). For example, within health it is often argued that the domain of medical expertise has expanded its boundaries so that more and more areas of culturally reproduced knowledge become sites of medical dominance and professional expertise (Illich, 1975). The areas of pregnancy and childbirth provide clear examples

of issues that were traditionally part of the life-world that have become increasingly systematised or 'medicalised' (Scambler, 1987). For example, it is argued that the introduction of forceps, which could only be used by trained medical professionals removed childbirth from the home into the hospital and under the control of the medical profession (Nettleton, 1995). Furthermore, one can see also how the doctor/patient consultation can be viewed as a site of strategic action based on achieving maximum outputs in minimum time (Barry et al, 2001). Thus consultation times are limited and the scope for communicative rationality to be achieved is severely restricted.

Mishler (1984) provides one of the first attempts to draw on the Habermasian concepts of system and life-world and apply them in a health research setting. Specifically Mishler (1984) conducted research into doctor/patient interaction, referring to the voice of medicine as part of the system and the patient as part of the life-world. Mishler (1984) concluded that when brought together, system and life-world spheres were essentially incompatible and prone to struggle. Analysing the interactions between patient and practitioner from 25 clinical consultations, Mishler suggests that most often the consultations were conducted in the voice of medicine and that the exchange between the patient and the practitioner is maintained within the practitioners control, an exchange that Mishler labelled as 'the unremarkable interview' (Barry et al, 2001). Therefore, Mishler argues that the clinical consultation was distorted in favour of the voice of the system vis-à-vis medicine and the techno-scientific discourse (Barry et al, 2001).

Building on Mishler's ideas, Barry et al (2001) studied 35 clinical consultations and suggest a typology of consultations based on four types: 1) 'Strictly medicine', where patients and practitioners spoke exclusively in the voice of medicine; 2) 'Lifeworld blocked', where patients expression of life-world concerns were blocked by the medical practitioner; 3) 'Lifeworld ignored', where patients spoke in the voice of the life-world whereas the practitioners spoke in the voice of medicine; and 4) 'Mutual lifeworld', where both practitioners and patients spoke in the voice of the lifeworld. Interestingly, Barry et al (2001) found that the best outcomes were achieved using the 'strictly medicine' or the 'mutual lifeworld' models, which supports Mishler's claims that bringing the voices of medicine and lifeworld together results in tensions and struggle. Barry et al (2001) go further to suggest that within the 'strictly medicine' model, the patients appeared to be happy to

conduct the consultation in the voice of medicine. Systems rationalisation, Barry et al (2001) suggest, is so pervasive that patients' own understanding and interpretations of their health and illness are mediated through the voice of medicine. Such life-world colonisation, Barry et al (2001) argue, may account for some patients' preferences to communicate in the voice of medicine:

"One possibility is that the patients themselves have become accustomed to thinking about themselves with the voice of medicine (their lifeworld has become colonised)".
(Barry et al, 2001; 501)

One of the most recent examples of Habermas' concepts of 'system' and life-world' applied to health research is provided by Britten (2008). Britten conducted research into prescribing practices and use of pharmaceuticals, exploring the different approaches taken by professionals and patients. Britten argues that current prescribing practices ignore patients' life-world concerns. As part of this, Britten argues that much of the available medicines information emphasises the benefits over the potential for harm, therefore ensuring systems imperatives by promoting the use of particular medicines. In claiming back the life-world, Britten found that patients often disregarded professional advice concerning the use of medicines and endeavoured to self manage their medicines without consultation with a certified medical professional. This type of patient behaviour was found to be a key concern of the health professionals, who viewed patient disregard for systems rationality as a challenge to their expertise. Therefore, there was a clear divide between patients' life-world perspectives and professionals' systems perspectives. Britten suggests that one way to re-couple system and life-world interests would be to enhance public involvement in strategic decision-making bodies, such as NICE and other medicines and research commissioning boards. Accordingly, it is suggested that life-world aims can be incorporated into key decisions regarding prescribing practices and use of medicines. My research takes Britten's suggestion as a starting point, by reflecting on how or indeed if life-world perspectives are incorporated into such decision-making committees.

In the next section a further important aspect of Habermas' thinking in relation to the wider debates surrounding public involvement in research will be considered. These include the advent of a 'legitimation crisis' in the

system and the ensuing rise of New Social Movement activity based on life-world perspectives.

Legitimation Crisis and the Rise of New Social Movements

As outlined above, Habermas (1987) talks of two distinct spheres of social life: the system and the life-world. It is argued that areas of the life-world have become increasingly systematised and driven by forms of instrumental rationality – achieving outputs in the most effective and efficient manner. Furthermore, it was shown how this argument can be applied to health care.

As part of the 'colonisation of the life-world' thesis, Habermas (1976) argued that increasing state intervention into areas of social life raised public expectations in the state by promising to deliver outputs in an effective and efficient manner (Braaten, 1991; Cuff et al, 2006). However, these expectations have not always been met when the state has failed to deliver. The result of this, Habermas argues, is a decline in public trust and respect for expert systems and organisations (Braaten, 1991), labelled as a 'legitimation crisis' (Habermas, 1976; Irwin, 2006; Scambler, 2001). For example, as applied to the health sphere, in the UK contested expert assessments of the risks of the triple-jab measles, mumps and rubella vaccine, genetically modified foods and Bovine Spongiform Encephalopathy (BSE) illustrate how expert decisions are open to question, frequently failing to offer a single line of advice. These examples indicate the potential fallibility of experts in the health sphere and the emergence of a legitimation crisis in this arena.

Furthermore, Habermas argued that as a result of this legitimation crisis, grassroots collective action begins to form. These forms of collective action have been labelled as New Social Movements (Habermas, 1981). According to Kelleher (2001) a fundamental aspect of New Social Movement Activity is their defence of parts of the life-world that have become colonised by the system. For example, in mental health service user activist movements arose in reaction against the dominance of psychiatry and a broadly medico-scientific model of mental health care, where the service user role was one of passivity (Crossley, 1999a). Therefore, the relevance of Habermas' theory of social life and his reflections on the system, life-world and New Social Movements appear to have some congruence with public involvement in

research and provide a useful theoretical framework through which to explore this research area. Further forms of New Social Movement will be explored in section 2.4.3 'grassroots approaches'.

Deliberative democracy

As a remedy to the legitimation crisis and a counter to the colonisation of the life-world, Habermas (1987) proposes a deliberative ideal based on new forms of participation and a reintegration of system and life-world aims (Habermas, 1987). Deliberative democracy provides an alternative to elitist approaches to decision-making. It is argued that deliberative democracy would enable expert decision-making systems to (re)gain legitimacy by becoming more transparent, opening the doors to new discursive practices and a plurality of voices (Pellizzoni, 2001; Scambler & Martin, 2001). Public involvement in health research is often advocated as a form of deliberative democracy and a mechanism to rectify a democratic deficit in expert decision-making systems (Barnes et al, 2004). As Davies and Burgess (2004; 350) argue:

"Deliberative governance strategies, in many areas of public policy, are one response to the uncertainties posed by the introduction of new technologies into complex, plural and unequal societies."

At a micro level, Habermas (1984; 1987) proposes the theory of communicative rationality as a way to transform deliberation and participation in practice (Davies & Burgess, 2004). Central to the theory of communicative rationality is the idea that open dialogue, free from distortion through coercion or manipulation, can lead to more democratic decision-making (Godin et al, 2007; Habermas, 1987). This discourse ethic would suggest that all participants would be entitled to present their perspectives, resulting in the 'best' argument succeeding, based on the validity of the argument, rather than involving manipulation or strategic action (Ploger, 2001). Davies and Burgess (2004), suggest two fundamental principles to ensure effective deliberation; competence and fairness. Competence is about an individual's legitimacy to speak and the validity that is associated with their claim. Fairness is concerned with the scope for engaging a wide range of voices and embracing a plurality of expertise (Davies & Burgess, 2004). It is through open and unconstrained dialogue that true cooperation, free from power, could exist and the life-world can reclaim its place in society (Cuff et

al, 2006; Fleming, 2001; Hayes & Houston, 2007). This unconstrained dialogue is labelled as 'an ideal speech situation' (Habermas 1976). Hayes and Houston (2007; 1001) provide a useful set of criteria that are necessary in order for an ideal speech situation to exist:

- *"Everyone affected by the issue in question is included in the dialogue provided they have the communicative ability to do so.*
- *Each of the participants is able to introduce, question and criticise any issue.*
- *Participants are able to express their attitudes and needs without restriction.*
- *Participants must have genuine empathy for others' perspectives and frames of reference.*
- *Power must be in check so that the only legitimate force is the better argument.*
- *Participants must try to achieve consensus based on reasoned argument and abandon communication where there is a lack of transparency and coercion is present".*

It is often recognised that such a situation, as outlined by Habermas (1987) is an *ideal* and as such is unlikely to exist in its entirety (Barnes et al, 2006; Hodge, 2005a). However, it does provide a useful set of criteria by which to reflect on public involvement in research decision-making settings. For example, Hodge (2005a) explored service user participation in a mental health forum using Habermas' theory of communicative rationality, in particular exploring the competence aspect of the theory. Using an ethnographic approach, Hodge (2005a; 168) selected a local mental health forum that was set up by the mental health service in order to *involve service users in the policy-making process*. Hodge found that within the mental health forum the style of communication was far from the Habermasian ideal speech situation. Hodge showed that the service users 'life-world' contributions to the forum were restricted, and bound within the remit of what was institutionally defined as acceptable talk and this served to reinforce the institutionally constructed service user identity:

"...the kind of discourse constructed by the system is far from communicatively rational. Participants are structured into adopting communicative roles that mirror the institutional identities created by the system, and these roles limit the forms of knowledge that can be drawn upon by occupants of different roles in discourse".
(Hodge, 2005; 178)

Hodge (2005a) highlights a potential difficulty with Habermas' ideal speech situation, namely, the conceptualisation of competence as unproblematic

when all speakers are considered as equal. Such an analysis fails to account for the institutional power dynamics that Hodge (2005a) reports were evident within the mental health forum. For example, as Hodge (2005a) notes, the dynamics between professional and patient in a clinical situation were often echoed in the mental health forum, limiting the opportunity for mental health service users to engage within the forum on their own terms. This finding may be of particular interest in relation to public involvement in health research and decision-making.

Summary of section

To conclude, this section has explored some of the key theoretical arguments proposed by Habermas and discussed by other commentators in relation to the area of health. Specifically Habermas' ideas concerning the 'system' and 'life-world' can be seen to have particular resonance in the area of public involvement in health research. According to Habermas, the public can be located within the realm of the life-world, whereas researchers and research organisations are part of the system. It is argued that as a result of a 'legitimation crisis' public trust and confidence in legitimacy of certified 'experts' has waned. Furthermore, it is argued that esoteric and elitist decision-making groups are failing to fulfil the criteria of liberal democracy. Consequently, public involvement in health research can be understood as a potential mechanism to re-couple system and life-world aims, opening up research decision-making settings to a plurality of expertise, brought in the form of the voice of the public.

In the next section, the broader literature concerned with the changes in the relationship between science and society will be considered. In particular, the idea of the 'democratic deficit' will be explored along with important reflections on the operation of power within deliberative spaces.

2.4.2. The relationship between science and society

In the previous section the work of Habermas was explored. In particular, Habermas' work is suggestive of a changing relationship between science and society, professionals and the public. In this section, these ideas will be considered in more detail. As Prior (2003) contends, during the later part of the 20th century there have been a number of developments that have led to

an emphasis on the accountability of medical and techno-scientific experts. A variety of public participation developments have ensued, public involvement in research being one of them. The literature highlights various schools of thought in relation to these developments. For example: proponents of late-modernity⁴ argue that contemporary society is framed by changes in the way that individuals relate to each other, organisations and expertise (Giddens, 1990, 1991); some theorists suggest a decline in public trust in science; technological and global developments have altered the way that the public can relate to science (Beck, 1992); and contemporary theories of consumption suggest a change in the relationship between consumption, personal identity and empowerment (Shaw & Aldridge; 2003).

A number of theorists have reflected on key changes in the nature of trust between the public and professional experts in society (Beck, 1992; Habermas, 1987; Irwin & Michael, 2003; Jasanoff, 2003; Wynne, 1996). For Habermas (1987), a decline in public faith in the institutions of science, politics and medicine should be viewed in relation to a 'legitimation crisis' (Braaten, 1991; Prior, 2003). Hess (2004) builds on this idea by suggesting that public trust in the scientific and medical institutions has declined for three primary reasons; a gap between public expectations of services and the reality of the services delivered, increased media attention to hospital errors and the impact of iatrogenic diseases. In a similar vein to those arguments proposed by Habermas, Giddens' (1990) ideas concerning the decline of public trust in expert systems and Beck's (1992) 'risk society', suggest a change in the relationship between science and society, professionals and the public. For example, Beck (1992) illustrated how expert systems have created a cycle of fallibility, whereby risk goes hand-in-hand with industrialisation and modernisation (Abbinnett, 2003). As Irwin and Michael (2003; 73) explain:

"Science, mediated as it is within and by these institutions, is often identified with those moments when things do not run smoothly and life becomes anything but predictable. The spate of problems and outright disasters that have entered popular culture recently has led to the public becoming deeply suspicious of the expert pronouncements made over, for example, the safety of the MMR vaccine, the appropriate measures to be taken for foot and mouth disease, and the release of genetically modified crops."

⁴ Late modernity is a term used to describe society based on a belief in the continued decline of traditional institutions that began during modernity and a view of the relationship between society and modern institutions as increasingly complex and uncertain, raising important concerns regarding trust in expert systems, self reflection and relationships with others (Jones, 2003; Giddens, 1990, 1991).

Similarly, Davies and Burgess (2004; 350) point to the *"uncertainties posed by the introduction of new technologies into complex, plural and unequal societies"*. Furthermore, along with a decline in public trust in science, it is suggested that healthcare decision-making organisations are subject to 'a democratic deficit' (Barnes, et al, 2006; Martin, 2008; Milewa et al, 1999). Specifically, the democratic deficit refers to:

"...a lack of institutionalised local accountability and an absence of direct local electoral control, with regard to decision-making in health care planning".

(Milewa et al, 1999; 446)

Public participation in healthcare decision-making and research is often cited as a response to this democratic deficit in healthcare (Barnes et al, 2006; Martin, 2008).

Therefore, as a result of such a 'crisis of trust' and a perceived democratic deficit in expert systems, it is argued that the inclusion of 'different ways of knowing' and a plurality of expertise brought by the inclusion of the public may restore public trust in expert systems and increase their accountability and transparency (McClellan & Shaw, 2005; Stilgoe et al, 2006). For example, as discussed in the previous section, Habermas suggests that forms of deliberative democracy should be introduced into these settings, in order to restore free and open dialogue and the power of the 'best' argument. Hence, public participation in healthcare decision-making and research can be regarded as mechanisms to remedy the 'democratic deficit' (Barnes et al, 2006) by increasing a plurality of expertise into organisations traditionally dominated by an expert elite.

However, the effects of opening up deliberative spaces as a remedy to the democratic deficit and a mechanism to re-establish trust need to be established. As Davies and Burgess (2004; 350) ask:

"The interesting question is whether, in equivalent contemporary spaces and processes, deliberative processes provide the practical solvents to scepticism, the crisis of trust and legitimacy dogging science, politics and policy-making?"

Furthermore, as Stilgoe et al (2006; 19) ask:

"Are we opening up expertise to new questions and perspectives, or are we just letting people see the experts at work?"

In attempting to address such questions, Barnes et al (2004) conducted research into public participation in 17 case studies in England. The case studies were drawn from two 'large English cities' and included senior citizens' forums, social service user group (which included mental health service users, older people and disabled people) and neighbourhood forums. Each case study provided an example of public dialogue with professionals and according to Barnes et al (2004; 268):

"All the case studies were selected as examples of ongoing dialogue between citizens and public officials rather than one-off consultation exercises."

The aims of the research were to understand the rules of engagement in such groups, the processes of deliberation and the impact of deliberation on statutory decision-making bodies. Amongst their findings, of most significance is their conclusion that traditional institutional norms are incredibly resilient to the involvement of the public, suggesting a limited impact of the public voice in public policy decision-making settings. For example, Barnes et al (2004) report that lay members expressed 'profound frustration' with lack of action taken as a result of their concerns and that they also felt 'fobbed off' as their concerns were deflected. As such, it is important to reflect on some of the various conceptualisations of power in deliberation that are suggested in the literature.

In section 2.4.1, Habermas' (1987) theory of communicative rationality and the 'ideal speech situation' were outlined. This normative framework is one way to explore deliberative practices and the operation of power based on the ability for the public to have a voice at the decision-making table and their opinion to be heard. However, as Hodge (2005a) argues, such a framework, whilst providing a useful starting point, does neglect other potential forms of power dynamic. For example, as previously discussed Hodge's (2005a, 2005b) work on service user involvement in a mental health trusts' service user forum highlights the inherent power dynamics within institutionally defined identities, i.e. professional versus patient. As a result, the most valid argument may be prevented from being voiced. For example as Pellizzoni (2001; 61) suggests, professional certification is most often

associated with competence and legitimacy to be seen as a credible source in decision-making groups:

"Definition of the competence necessary to take part in discussion is often tied to professional qualification..."

Such an analysis appears to be in keeping with an early Foucauldian analysis of power, whereby power operates as an invisible, diffuse entity that regulates relations between individuals (O'Farrell, 2005; Pease, 2002). Internalized social norms that act as regulators of power ensure that individuals adjust their behaviour in order to assimilate with socially ascribed norms and values (Clegg, 1989). These norms and values can help to structure society in order that it functions in an effective way. Accordingly, competence to speak is often associated with professional ways of knowing, whilst patienthood is often associated with inferior ways of knowing. As Fischer (1993; 166) suggests:

"For him [Foucault] intellectual technologies such as policy science do more than asymmetrically distort communication; their discursive practices constitute the very objects of communication themselves."

These are important issues to take into consideration when exploring public involvement in research. Lukes' (2005), 'three dimensional view of power' provides a further analytic lens for considering the operation of power within decision-making spaces. In contrast to Habermas' focus on communication in decision-making spaces, Lukes (2005) proposes that in order to establish the operation of power in deliberative groups, greater attention should be given to what is *not* said or done. This incorporates ways that agenda items are suppressed or individuals' are prevented from expressing their opinions (Crossley, 2005; Lukes, 2005). Furthermore, Lukes' (2005) analysis suggests that decision-making groups' norms and values are constructed, shaped and filtered in the interests of those with the power:

"The three dimensional view of power shows that the culture of the organisation is important in the decision-making process. The socially constructed and culturally patterned behaviour of groups, and the practices of institutions are implicitly connected to the exercise of power".
(Gunn, 2008; 254)

Building on this, a key part of Lukes' analysis is the idea of 'real' interests. Lukes' (2005) suggests that 'real' interests are what an individual would do

under ideal democratic circumstances. However, Lukes' proposes that an individual's real interests may be unknown to the individual due to the processes of normalization through which their interests are actualized. This idea appears to bear some resemblance to the Marxist idea of 'false consciousness'. Specifically related to a class system in society, Marx suggested a 'false consciousness' to describe the way that subordinate classes readily comply with the dominant ideologies of the upper classes because they have been socialised into these beliefs, values and ideas. In other words their perception of reality is false (Jones, 2003).

Of course Lukes' analysis of power in decision-making settings is not without its critics. For example, Clegg (1989), amongst others, highlights the difficulty with revealing what 'real' interests are, as Lukes does not provide a model for doing this. Clegg also suggests that 'real' interests could be confused with what are simply different perspectives. Lukes (2005) admits that 'real' interests is a difficult concept to reveal. However, it is this complexity that makes the power in decision-making spaces so pervasive:

"[Power] is at its most effective when least accessible to observation, to actors and observers alike, thereby presenting empirically minded social scientists with a neat paradox"
(Lukes, 2005: 64).

Drawing on Lukes' ideas, Gaventa (2005) talks about the importance of the power associated with the *spaces* and the *places* where public participation occurs. In other words, Gaventa (2005) claims the deliberative space in which public participation takes place; either provided (or closed), invited, or claimed (created) provides some indication of whose interests are met within the parameters of that space. Provided, or closed, spaces are those in which decisions are made by a minority group for the majority. Moving along the continuum, invited spaces are essentially closed spaces which have begun to operate in a more transparent manner, increasingly engaging with wider public opinion, however essentially remaining institutionalised. Claimed spaces are argued to have a greater 'grassroots' foundation and are created out of a common interest or concern with the social and political world (Gaventa, 2005). In turn, this can help us to think about how the voice of the public may (or may not) be facilitated in these spaces. For example, one may consider that the impact of the public in decision-making settings may be more difficult in provided spaces than it would be in invited spaces, as

closed forms of decision making spaces may be subject to embedded institutional norms and values to a greater degree than invited spaces. Therefore, Gaventa's Ideas (2005) provide a way of reflecting on the context and process of public involvement in research.

Having considered the potential for power to distort public involvement in healthcare and health research, I will now turn to consider the argument that public involvement may 'empower' the public. Section one of the literature indicated that such a claim is made in the health policy literature (Hanley et al, 2004). Therefore, in the next section I will briefly explore some of the literature concerned with empowerment.

Empowerment

As illustrated in the first part of this literature review, within health policy literature an empowerment claim is made suggesting that public involvement in research is in some way 'empowering' for the public. However, whilst 'empowerment' is generally regarded as implicitly 'good', there is little clarity on what this concept actually means (Laverack, 2005; Small & Rhodes, 2000; Starkey, 2003).

A dictionary definition of empowerment is as follows:

"Empower: to give power or authority to; to authorize; to give ability to; to enable or permit".
(Collins English Dictionary, 1993)

Drawing on the dictionary definition, empowerment appears to be about one individual bestowing power upon another. This model of empowerment is common to the health policy literature. For example, within health policy, references to empowerment seem to be about health professionals providing patients and service users with opportunities for increased 'choice and voice' in the healthcare system (Clarke, 2005). In this way, empowerment is based on consumerist notions of the rights of healthcare consumers to make their own healthcare choices when provided with a range of information and options by healthcare professionals. In promoting choice, consumers are argued to be 'active and independent agents' able to make healthcare decisions based on their own personal preferences (Clarke, 2005). Furthermore, within the ideology of healthcare consumerism, in promoting

'voice', patients and service users are increasingly consulted for their opinions and involved in healthcare decision-making. Therefore, inherent to the policy construction of patient empowerment, through enhanced 'choice and voice', are notions of individual control and moreover personal responsibility (Anderson, 1996).

Building on this, the Expert Patient Programme (DH, 2001) is founded on the idea of 'empowering' patients to take control over their health through a programme of self-management (McDonald et al, 2007; Taylor & Bury, 2007). In order to become 'expert patients', patients with chronic illnesses are invited to attend weekly sessions as part of a structured training course that typically runs over a six-week period (Taylor & Bury, 2007). Throughout the training course patients are taught how to deal with issues directly related to their chronic illness such as pain management, fatigue and use of medications, as well as wider social consequences of their ill health such as effective communication and managing personal relationships (Taylor & Bury, 2007). Again, the focus on personal control and personal responsibility is suggested to empower patients by moving the control from the professional's to the patient's hands (Wilson et al, 2007).

However, the Expert Patient Programme, and wider consumerist discourses of empowerment have been critiqued for the potential that they might serve to reinforce the dominance of professional power over the patient. As Fox et al (2005; 1300) suggest:

"While there is a logic to developing patient expertise in an age where one in three people have a chronic illness or disability, and medical interventions manage rather than cure these conditions, the notion of the expert patient ignores entrenched professional power and structural constraints to do with access to resources and conflates experience and education".

In other words, the dominant biomedical discourse is central in defining the terms of the Expert Patient Programme, and more widely what choices are available to patients and how these choices are conveyed to patients (Clarke, 2005). Such a construction of empowerment has been contested as it essentially maintains power divisions between those who can empower and those who need empowering (Pease, 2002). Consequently, the notion of 'patient empowerment' is arguably closely guarded within professional terms, with the professional acting as the 'agent' of empowerment. Furthermore,

Wilson (2001) argues that the Expert Patient programme leads to the medicalisation of patients' home life, with biomedicine effectively 'seeping' into increasing areas of life beyond those within medical remit.

In addition, McDonald et al (2007; 434) suggest that the discourse of empowerment within health policy literature, with particular reference to the Expert Patient Programme is a '*mechanism for shifting responsibility from the state to the patient*'. Consequently, health policy preferences for empowerment may actually be experienced by some patients as disempowering if their preference is for greater professional intervention. As Aujoulat et al (2008) argue, the common construction of empowerment assumes that patients value being in control of medical decisions over other aspects of their illness experience, an assumption which has been contested by some commentators (Fisher, 2008; Wilson, 2001). Therefore, such critiques of the consumerist model of empowerment remind us of the inherent role of 'power' in empowerment.

In a challenge to consumerist constructions of empowerment, feminist and liberational constructions of empowerment attempt to redefine ingrained power imbalances and are therefore concerned with individuals empowering *themselves* (Stakey, 2003). Empowerment is understood as a mechanism to change the division of power and challenge oppression and exclusion (Starkey, 2003). Beresford and Evans (1999) talk about the empowering effect of public involvement in research as the 'emancipation of research participants'. Rather than being involved as passive research recipients, through the process of involvement in research it is suggested that "*...participants have the direct capacity and opportunity to make change*" (Beresford, 2002; 97). Consequently, liberational constructions of empowerment concern direct changes to the existing healthcare system, whereas consumerist constructions of empowerment are framed within the existing system (Laverack, 2005).

Due to the intrinsic complexity associated with empowerment, some commentators have attempted to define key principles necessary for public empowerment through involvement in healthcare decision-making and research. For example, Small and Rhodes (2000) cite, Barnes and Walker's (1996) eight key principles of empowerment:

1. Empowerment should be concerned with personal development
2. Empowerment should increase individual's abilities to take control of their lives.
3. The empowerment of one person should not result in the exploitation of another.
4. Empowerment should not be viewed as a sum zero.
5. Empowerment must be reinforced at all levels within the health service.
6. Empowerment of those who use services does not remove the responsibilities of those who produce them.
7. Empowerment should not be used as a way to reduce resources.
8. Empowerment should be a collective as well as an individual process.

It is suggested that such principles of empowerment may provide useful guidelines when assessing the 'empowering' claims of health organisations and developments.

Summary of section

In this section, the literature concerned with the changing relationship between science and society has been considered. In particular, it has been suggested that a number of developments can be linked to the emergence of participatory forms of governance: a decline in public trust and faith in science, politics and medicine (Beck, 1994; Giddens, 1990, 1991; Prior, 2003); uncertainties associated with the development of new technologies (Beck, 1994; Davies & Burgess, 2004) and a democratic deficit in healthcare decision-making settings (Barnes et al, 2006; Martin, 2008).

However, the review has indicated that deliberative decision-making spaces should not be automatically considered the solution to these developments. Moreover, it would seem that the operation of power within these spaces should be considered. For Habermas, this would entail an analysis of the conversation within decision-making groups, with truly democratic decision-making spaces complying with an ideal speech situation. On the other hand, it has been suggested that the construction of norms and values should be taken into consideration as the dominant discourse may be responsible for shaping individuals ideas, again preventing truly democratic decision-making spaces (Lukes, 2005).

Furthermore, this section has presented a brief overview of the key debates associated with empowerment. It is suggested that such arguments need to be kept in mind given the health policy claim that public involvement in research provides a mechanism for empowering the public.

Having so far considered some of the broad sociological reflections on the changing relationship between science and society, in the next section, the literature review will explore one particular aspect of this in more detail. Specifically, the next section is concerned with the emergence of grassroots approaches to involvement, which present a set of examples on how the sociological reflections from this section are played out in practice.

2.4.3. Grassroots approaches to public involvement in healthcare and research

In this section of the literature review, the literature regarding the emergence of grassroots movements in health will be considered. This literature is important as it provides alternative ways of understanding the development of public involvement in health research, alongside the political discourse that was considered in section one of the literature review.

Petersen (1984) points to the increasing number of grassroots movements that emerged during the 1970s and 1980s in relation to citizen disputes with issues such as; the fear of risks related to technological developments, central encroachment on traditional values and lifestyle and campaigns for equity, for example the women's, disability and environmental movements (Croft & Beresford, 1992). One rationale for the rise of such grassroots movements is provided by Habermas (1981) in his accounts of 'New Social Movements', which are argued to have arisen as a result of a 'legitimation crisis' and the colonisation of the life-world (as explored in section 2.4.1 'Habermas' critical theory of social life'). New Social Movement activity, consisting of individuals with specific experience and knowledge, works to promote the (re)integration of local situated knowledges (or the life-world) into exclusive expert decision-making process (Kelleher, 2001).

In health care, grassroots movements can be broadly linked to the formation of illness specific groups, which are argued to directly challenge medical

policy and make demands on the current provision and access to therapeutic treatments (Allsop et al, 2004). These groups may also question the aims and goals of the medical and scientific worlds, including research. Allsop et al (2004) label these groups as 'health consumer groups', whereas Hess (2004) refers to them as 'health social movements' and Brown and Zavestoski (2004) talk of 'embodied social movements'. For the purposes of this discussion they will be referred to as health social movements (HSMs).

It is argued that HSMs have been formed through individuals experiencing illness finding commonalities with others in similar situations and are thus identity based, centred on some degree of shared illness identity. Scott (1990) outlines two types of social movement: those based on exclusion from citizenship rights; and those based on exclusion from processes of elite negotiation and demanding participation rights. In many ways it could be argued that health social movements have transcended from the first category to the second. Initially, many health activist groups were concerned with gaining citizenship rights and increasing public recognition and acceptance of particular health conditions. However, more recently increased attention has been paid to the rights of the public to be part of the professional decision-making processes. Brown and Zavestoski (2004; 679) define HSMs as:

"...collective challenges to medical policy, public health policy and politics, belief systems, research and practice which include an array of formal and informal organisations, supporters, networks of cooperation and media".

It appears that an important aspect of HSMs is that they consist of individuals *with* a specific condition, rather than individuals *representing* those with particular conditions. The focus is on the personal and individual accounts of illness, yet the strength of the groups is rooted in collective action (Allsop et al, 2004). Byrne (1997) states that in order for a social movement to initially form and then remain strong, group members must identify with the shared values and moral principles of the group, making these a high priority. As part of this, Byrne (1997) believes that involvement in a social movement is a symbolic statement about an individual, evoking a sense of belonging, locating the individual within a group that has a central goal, aim and identity.

It would seem that the specific function and focus of HSMs varies between each group. However, from the literature it is clear that most are concerned with improving health care conditions and the availability of, and access to, therapeutic treatments (Brown & Zavestoski, 2004). There is also a key emphasis on the discourse of empowerment – *"People are concerned with speaking and acting for themselves"*. (Croft & Beresford, 1992; 23)

Whilst not directly discussing HSMs, work by Callon and Rabeharisoa (2003) on patient organisations and the co-production of knowledge, has clear resonance with this field. Callon and Rabeharisoa (2003) point to three types of patient organisation, based on their relationship with professional groups:

- Auxiliary organisations – groups based on recognition of the difference between experiential expertise and professional certified expertise. Some auxiliary organisations work in collaboration with professional groups, whereas other auxiliary organisations acquire certified expertise comparable with the professional groups.
- Opponent organisations – groups that reject techno-scientific discourse.
- Partner organisations – groups that work collaboratively with professional groups.

Much of the literature appears to identify HSMs as a form of auxiliary organisation. For example, Epstein (1995, 1996) points to the way that HIV/AIDS treatment activists acquired a thorough understanding of the scientific methods and terminology in order to contribute to scientific and policy discussions and challenge what is presented as 'scientific fact' and 'knowledge' (as discussed below).

It is commonly cited that the latter half of the 1960s marked the beginnings of HSMs that were openly visible to the media and public gaze (Martin, 2001; Allsop et al, 2004). During this period other rights based movements had gained momentum, such as the women's rights movement and the black civil rights movement in America. It could be argued that these movements provided models upon which HSMs could be based (Scotch, 1989). For example, the natural childbirth movement, a reaction against the medicalisation of childbirth, is argued to have emerged on the back of the growing feminist movement (Allsop et al 2004).

Furthermore, there are a number of widely documented HSMs. For example, the disabled people's movement emerged as a result of local groups of people with disabilities, who rejected the medical model of disability, grouping together to present a united group. The disabled people's movement campaigned for civil rights and demanded to be afforded the same rights as able-bodied people (Beresford, 2002; Scotch, 1989). Similarly, some groups within the mental health movement campaigned against the medical model of illness, and held an anti-psychiatry stance. Campaigners expressed their strong desire to be regarded as people first, rather than patients, and were concerned with mental health ward conditions, quality of life and the use of particular treatments (Wallcraft and Bryant, 2003). The beginnings of the contemporary mental health movement has been traced to group protest against the closure of a day hospital in London (Crossley, 1999a, 1999b), therefore demonstrating the grassroots nature of the service user movement. The Alzheimer's movement is a relatively recent movement to emerge and has been concerned with *"transforming senility from a private family matter to a medical epidemic demanding public concern"* (Beard, 2004; 798). Other health social movements include HIV/AIDS treatment activism, which emerged during the 1980s (Epstein, 1995), on the back of the gay rights political movement (Wachter, 1992). It is argued that HIV/AIDS treatment activists emerged in order to challenge the scientific failure to provide a cure for HIV/AIDS (Crossley, 1998). In other words, the legitimacy of scientific institutions were exposed to doubt due to their inability to meet patients' expectations, i.e. a legitimacy crisis. In the USA, HIV/AIDS treatment activists campaigned for more biomedical research and clinical trials to be conducted and for all patients to be given the option of testing experimental treatments. In order to be heard within the scientific institutions, the activists' tactics included sabotaging research (e.g. not complying to the conditions of control and treatment arms of clinical trials) and also becoming proficient in the techno-scientific discourse (as will be explored in the next section). Indeed, such has been the success of the HIV/AIDS treatment activists in bringing life-world concerns to the research table that Epstein (1995; 414) concluded:

"...the AIDS movement is indeed the first social movement in the United States to accomplish the mass conversion of disease 'victims' into activist-experts, and in that sense the AIDS movement stands alone, even as it begins to serve as a model for others".

Building on this, Brown and Zavestoski (2004) argue that one of the key reasons why HSMs have emerged is in response to a legitimization crisis. This argument highlights the 'democratic deficit' claim for involvement based on the limited opportunities that have traditionally been made available for public participation in policy debates. Effectively, claiming that decision-making processes have become increasingly elusive and removed from the public sphere. Therefore, health and medical issues that are discussed and given priority are those that are judged to be important by techno-scientific decision makers with decision-making rights. Following Brown and Zavestoski's (2004) argument, HSMs are considered to be a reaction against the dominance of science in the decision and policy-making arena. This clearly echoes Habermasian ideas of HSMs as a response to a 'colonization of the life-world' (Kelleher 1999).

Furthermore, beyond serving as a mechanism to (re) couple system and life-world aims, in acquiring in-depth understanding of the scientific discourse surrounding a specific illness and also having first hand experience of that illness, some have argued that HSMs present a 'powerful challenge' to the traditional dominance of biomedical science (Hess, 2004). Within the HSM literature, Hess (2004) labels this form of knowledge as 'counter-expertise' and argues that the medical professions and scientific research communities have had to adapt and undergo *epistemic changes* as a result of challenges posed by some Health Social Movements. However, as will be explored in the next section, the extent to which such groups present a challenge to the techno-scientific discourse is contested by some commentators. Such a question is central to the discourse surrounding public involvement in research. Does an alleged democratisation of knowledge, coupled with the availability of new participatory spaces, lead to a change in the way that decisions are made and their outcome? These questions remain unanswered.

In the next section, these questions are further considered as the literature concerning the changing relationship between lay and professional expertise will be explored.

2.4.4. The changing relationship between lay and professional expertise

So far, section two of the literature review has explored arguments concerning the changing relationship between science and society, professionals and the public. It has been argued that the emergence of decision-making spaces that are orientated towards more deliberative processes of operation may offer the potential for the inclusion of a plurality of expertise, and accordingly the involvement of lay people. In accounting for the emergence of HSMs, Hess (2004) argued that lay knowledge can provide a form of 'counter expertise' and a challenge to 'traditional' forms of knowledge. However, how is the contribution of lay people distinct from that of health professionals? In order to begin to reflect on this question, in this section of the review the literature pertaining to lay and professional forms of knowledge and expertise will be explored.

It is reasonably clear that since the Enlightenment period, decision-making processes in healthcare and health research have traditionally been the domain of professional expertise (Jasanoff, 2003; Roberts, 1999). In his work on the health professions, Freidson (1986) provides an account of professional power, or medical expertise, founded upon what is referred to as 'formal knowledge' (Scambler, 1987). Formal knowledge is that which is known only to a minority elite group, achieved through education and certification, and is largely inaccessible and incomprehensible to the general population. Professional control of such formal knowledge is maintained through their unique position, bestowing an expert elite exclusive authority in constructing and defining what constitutes knowledge (Pollock, 2005; Bosk, 2006). As Jasanoff (2003; 394) explains:

"...what operates as credible expertise in any society corresponds to its distinctive civic epistemology: the criteria by which members of that society systematically evaluate the validity of public knowledge".

Accordingly, it is clear that professional formal knowledge, associated with such 'markers of excellence' as certification and accreditation, has set the standard and the criteria against which all claims to knowledge have been judged.

However, as outlined in the previous section, it is argued that during the last few decades the credibility of professional claims to expertise have been questioned and have been subject to a 'legitimation crisis' (Habermas, 1976; Prior, 2003). Knowledge and expertise have been shown to be subject to political and cultural influences (Jasanoff, 2003b). As a result, there are a growing number of examples of the changing dynamics between professional and lay forms of knowledge, with expertise viewed as increasingly contested within late modern societies (Beck, 1992; Giddens, 1991; McClean & Shaw, 2005). Some commentators attribute this to a 'democratisation of knowledge' (Prior, 2003; Turner, 2001) – opening the closed doors of science and scientific decision-making to the public gaze.

From a broad healthcare perspective, the changing relationship between service providers and service users is evident in a number of developments, for example: emphasis is now placed on the necessity for health care providers to offer public health information, as this is considered to be a 'right' of the layperson in the current health care environment (Henwood et al 2003); within the medical practice there is an emphasis on 'shared decision-making' (Edwards & Elwyn, 2006; Prior, 2003) and the relationship between professional and patient in the health care environment is said to be one of 'active negotiation' (Bury, 1997). The growing theoretical attention paid to lay beliefs and the increasing reference to 'consumers' or 'partners' could potentially signal an alternative view of the medical encounter, one which has been labelled by Tuckett et al (1985) as a 'meeting between experts'.

Specifically related to this thesis, public involvement in research potentially signals a changing relationship between professionals and the public. What is apparent is that public involvement in healthcare and health research implies that different forms of knowledge and ways of knowing are brought into the health research and decision-making processes. Although often overlooked within health policy discourse, central to discussions about public involvement in research are questions regarding the nature of expertise itself and its epistemological underpinnings, moreover what counts as credible expertise in research (Davies & Burgess, 2004)?

Over the last thirty years considerable academic attention has been paid to the construction of lay knowledge and the potential that lay knowledge may

contribute towards existing bodies of 'expertise' (Popay & Williams, 1996). Collins and Evans (2007) point to Kuhn's eminent book, 'The Structure of Scientific Revolutions' (1962), in which the logical positivism of the natural sciences was openly critiqued, as marking the beginnings of such an interest. Within Kuhn's account, the central notion that science represents an objective and value free process was held to doubt (McCormick et al, 2004). In highlighting the embedded nature of values in scientific decision-making, the potential for such processes to be broadened out beyond a scientific elite is argued to be a necessary element of the democratic ideal (Krimsky, 1984; McCormick et al, 2004). Bury (1997; 19), quoting Good (1994), provides a clear argument in support of this:

"Rather than scientific medicine being treated as if it were a 'mirror of nature' it should be regarded...as a 'rich cultural language linked to a highly specialised version of reality and system of social relations' including 'deep moral concerns' as well as technical ones. Similarly, lay practices and interpretations should be studied in order to reveal the 'diverse interpretative practices through which illness realities are constructed, authorized and contested in personal lives and social institutions"

Given the case that is made for the inclusion of lay health knowledge in healthcare decision-making and research, what does this term actually mean? Essentially, it is argued that lay health knowledge refers to the implicit, or situated, knowledge, experience and understanding that an individual has about their body, health, illness and use of services and treatments (Caron-Flinterman et al, 2005a). It is knowledge created through common sense explanations, knowledge that is passed down through family generations, and shared within communities and societies (Barry et al, 2001).

In distinguishing between lay and professional forms of knowledge, Brown (1992; 267) argues that:

"Professionals generally concern themselves with disease processes, while lay people focus on the personal experience of illness... From the professional perspective, symptoms and diseases universally affect all people, yet lay perceptions and experience exhibit great cultural variation. Similarly, lay exploratory approaches often utilize various causal models that run counter to scientific notions of etiology".

Brown (1992) appears to suggest that lay health knowledge is distinct from that of professional health knowledge, with lay knowledge often contrasted with that of professional knowledge. Professional knowledge is 'universalistic', whereas lay knowledge is 'situated' (Weiner, 2009). Building on Brown's suggestions, Popay and Williams (1996) argue that lay knowledge is essential for developing holistic accounts and explanations, particularly in relation to chronic illness and disability. For example, in some areas of disease it is argued that the expertise of the layperson is greater than that of the certified expert. Stevenson and Scambler (2005) explain that patients with chronic illnesses often acquire expertise about their condition over a sustained period of time. Consequently, they may become better versed in the depth and detail of their symptoms and preferable treatment options and an overall understanding of their illness than their consultant, who often deals with a broad surface level understanding of many patients. Thus, there are parallels between constructions of lay knowledge and feminist accounts of 'situated knowledges' (Haraway, 1991) and 'stand-point epistemology' (Cuff et al; Tew et al, 2006). Stand-point theorists basically assert that it is impossible to understand what a phenomenon is like unless one has directly experienced that phenomenon (Cuff et al, 2006; Tew et al, 2006).

Despite this, it is argued that lay knowledge is often regarded as subjective opinion, inferior or 'misguided ways of knowing' (Popay & Williams, 1996), as '*flawed scientific knowledge*' or moreover '*as something other than knowledge altogether*' (Horlick-Jones et al, 2007; Williams & Popay, 2001; 31). As such, the legitimacy of the contribution of lay knowledge in health and scientific decision-making settings has often been queried. The attitude of the professional towards the public and vice versa will often determine whether or not each party member is viewed as a credible agent. Within research settings, many researchers are still driven by the epistemology of logical positivism, striving for objectivity and rational claims to universality (Caron-Flinterman, 2005). These values can make it difficult for some researchers to view experiential knowledge as valid, as it can challenge the rigidity of strict objective methodologies (Thompson et al, 2009; Ward et al, 2009).

In his exploration of expertise, Prior (2003), points to the development in the language used in the sociological literature regarding lay knowledge and

expertise. Prior (2003) draws on a development within the sociological literature that has advocated the significance of 'lay beliefs' or 'lay accounts' about health and illness, changing to 'lay knowledge' and then further developing with the introduction of the 'lay expert'. Alongside these developments in terminology, Prior (2003) also points to the construction of 'lay epidemiology', referring to what was previously regarded as lay understandings of disease causation. For example Davison et al (1991) proposed the term 'lay epidemiology' to refer to the development of lay beliefs and knowledge regarding the markers of increased risk from certain diseases and illness. The implication here appears to be clear, with the label 'expert' carrying much more of an association with a certified form of knowing, whereas 'belief' would imply a way of knowing that is more open to interpretation and question, and consequently more likely to be discredited as 'unproven' and potentially unimportant by the scientific community (Williams & Popay, 2001). The development in the language would suggest increasing weight being given to lay ways of knowing.

Given the apparent contrasting nature of lay knowledge in respect to that of professional knowledge, it is common for accounts to suggest a 'clash of cultures between the expert and the lay' (Irwin & Michael, 2003). Williams and Popay (1994) suggest that lay knowledge provides a challenge to expert knowledge for two primary reasons: firstly, it challenges the 'objectivity' of expert knowledge, thereby providing an epistemic challenge; and secondly, it provides a political challenge to the '*institutional power of expert knowledge in general*' (Williams & Popay, 1994; 120). Consequently, there are a number of seminal accounts that document the apparent differences between expertise generated through experience and expertise generated through certification, and the resultant conflicts that occur when these two forms of knowledge are brought together. These accounts span from environmental health scandals through to specific disease related social movements.

In the area of adverse environmental incidents, Wynne (1996) provides a clear account of such differences in his study of the social interaction between sheep farmers and scientists in the Lake District following the radioactive fallout from the 1986 Chernobyl accident. Wynne's research illustrates the problematical relationship between the local, situated expertise of the sheep farmers and the general certified expertise of the scientists. Wynne explains how scientific guidance that was given to the local sheep

farmers, regarding their cattle and the risks of contamination from radioactive waste lacked consistency. Initially the scientists proclaimed that the effects of the nuclear fallout were minimal. However 6 weeks later this guidance was retracted and a ban placed on the *movement and slaughter of sheep* from some of the effected areas (Wynne, 1986). Naturally, Wynne argues that such inconsistent scientific advice reduced the farmers' trust in the scientific experts. However, arguably of greater impact on the relationship between the sheep farmers and the scientists, was the scientists' disregard of the farmers' own local knowledge. For example, Wynne (1986) explains how the scientists advised the sheep farmers' on where to let their sheep graze in order to avoid the effects of the radioactive fallout, ignoring the farmers' own local knowledge of the environment and the suitability of grazing land. According to Wynne, the scientists disregard for local knowledge led to differences of opinion between the scientists and the sheep farmers, with the farmers feeling that their identity and expertise was under challenge:

"Naturally the farmers felt that their whole identity was under threat from outside interventions based upon what they saw as not ignorant but arrogant experts who did not recognise what was the central currency of the farmer's social identity, namely their specialist hill-farming expertise."
(Wynne, 1996; 36)

Wynne's study (1986) provides one example of the complexity inherent within lay and professional constructions of credible expertise. Brown (1992) provides another influential example of lay and professional interaction over environmental incidents. Building on earlier research into childhood leukaemia in Woburn Massachusetts in the USA, Brown (1987, 1992) talks of the development of 'popular epidemiology' as providing a 'bridge' between lay and expert perspectives. The Woburn childhood leukaemia case concerned the efforts of local families and community activists in successfully proving that a high rate of childhood leukaemia in the area was linked to industrial toxins that were being leaked into the local residential water supply. In working with scientists and public health officials, the families and community activists challenged aspects of the scientific method, such as required levels of 'statistic significance' and sample sizes and also drew attention to lay knowledge of causal linkages, in order for research in this area to be considered significant. Brown (1987, 1992) labelled this form of public and community activism as 'popular epidemiology':

"Popular epidemiology is the process by which laypersons gather scientific data and other information, and also direct and marshal the knowledge and resources of experts in order to understand the epidemiology of disease...Further it involves social movements, utilises political and judicial approaches to remedies and challenges basic assumptions of traditional epidemiology, risk assessment and public health regulation".

(Brown, 1992; 269)

Williams and Popay (1994) provide a further example of the development and mobilisation of lay epidemiology, in their exploration of the Camelford water poisoning. The Camelford water poisoning incident concerned a toxic spillage into the treated water reservoir that supplied local residents in the Camelford area. Following this incident, local residents and holiday makers who were in the area at the time, reported a number of different health impacts that appeared to be related to the toxic spillage. This was met by a government assessment of the initial and long-term health effects of the contaminated water on people's health. The official expert panel denied a correlation between the spillage and long term health effects. However, the local residents strongly disagreed, and some of the local residents formed an activist group to dispute the conclusions. As part of this, the local residents developed an evidence base on the relationship between the toxic waste and Alzheimer's disease based on a review of the research and their own knowledge and experience. Whilst this action was dismissed by the government, over two decades later residents are still calling for the case to be reviewed. Williams and Popay (1994) argue that what this case adds to the literature is a further example of how lay epidemiology can provide a sophisticated critique of established practices in health:

"This kind of mobilisation of lay knowledge expresses a critique of the manner in which health risks are conceptualised and measured, a profound mistrust of the experts given responsibility for doing the defining and a rejection of existing public health policies".

(Williams & Popay, 1994; 134)

In the areas of disease specific activism, Epstein (1995, 1996) provides a highly cited account of lay/professional interaction, in his research concerning HIV/AIDS activists' relations with the scientific experts. Pointing to the 'credibility tactics' employed in order to be seen as legitimate experts, Epstein (1995, 1996) reflects on the HIV/AIDS activists eventual elevation to the position of credible experts. Drawing on extensive documentary, interview and observational data, Epstein (1995), points to the situated

knowledge of the HIV/AIDS activists as providing the initial 'challenge' to the professional experts. In this case, the challenge was particularly related to HIV/AIDS activists gaining access to clinical trials and to the activists' role in rapidly pushing through the approval of experimental treatments. However, in order to be seen as a credible source and to have an effective voice amongst the scientific experts, the activists underwent a process of *expertification* whereby they were able to converse in the dominant techno-scientific discourse. Epstein (1995; 426) argues that their unique position was crucial to the activists' success in achieving the status of credible experts:

"...they [HIV/AIDS activists] were able to make effective use of existing differences of opinion among credentialed experts; and that they [HIV/AIDS activists] were able to weave back and forth between epistemological, methodological, political, and ethical claims to construct powerful arguments that proved effective in both specialized and public arenas."

Epstein (1995) suggests that due to their unique claim to credibility, based on both experiential knowledge and certified knowledge, the HIV/AIDS activists were able to present a powerful challenge to the certified experts. However, given that the HIV/AIDS activists in Epstein's study had to become proficient in the dominant discourse, in order to be regarded as a credible source of knowledge, one may query the extent to which the activists provided an epistemic challenge to the existing professional group.

In a similar account to that provided by Epstein (1995, 1996), McCormick et al (2003, 2004), discuss the impact of breast cancer activism on breast cancer research in the USA. McCormick et al (2003, 2004) provide examples of breast cancer activist groups in Massachusetts and San Francisco Bay *'advancing research, educating the public and changing policy about environmental causes of breast cancer'* (McCormick et al, 2003; 564). Such a link between health activism and public involvement in research, as found within the examples from Brown (1987, 1992), Epstein (1995, 1996) and McCormick et al (2003, 2004) amongst others, suggests a clear role for the public in challenging established knowledge, practice or recommendations.

However, in contrast to this argument some commentators have questioned the extent to which public or experiential expertise may provide a challenge to professional expertise. For example Kerr et al (2007) provide an account

of a study concerning public and professional interaction during three public events about genetics. Drawing on data collected through a combination of discourse analysis and ethnography, Kerr et al (2007) found that the potential to forge a public dialogue between the public and the professional was 'muted'. This was largely because the lay members were found to be deferential towards the scientific role, privileging certified forms of knowledge over their own experiential knowledge. As Kerr et al (2007; 408) concluded:

"This makes us question the extent to which lay people can ever expose scientific error and hubris, given that the layness we found was so fragile, easily compromised and so readily aligned with expert positions by both scientific experts and others".

In a different setting, Weiner (2009) also considered the interaction of lay and professional forms of knowledge and the potential for lay knowledge to pose a challenge to certified knowledge. Weiner's ethnographic study looked at the merger of a patient led heart charity and a professional organisation in heart health. Weiner argues that the merger of the two organisations, and accordingly the two different forms of rationality, was of strategic importance used to secure resources and as such cannot be regarded as a move towards the democratisation of knowledge or a partnership between lay and professional forms of knowledge. Therefore, Weiner concludes that it may be inappropriate to see lay involvement as involving a challenge to traditional modes of expertise or knowledge production.

Hitherto, the constructions of lay knowledge have been considered and various examples have been provided to illustrate how lay and professional forms of knowledge may work together in practice. The literature appears to suggest that there is little agreement about what constitutes legitimate lay claims to knowledge and decision-making. In this respect, questions about who to involve in deliberative forums remain. In the light of this, a number of commentators have attempted to provide frameworks and models to account for expertise in decision-making settings. These will now be explored.

2.4.5. Models of expertise

As explored in the previous section, there is little agreement about what constitutes legitimate expertise, particularly within the health research environment, where there has traditionally been a strong commitment to

positivist conceptions of knowledge (Popay and Williams, 1996). Debates concerning the nature of expertise and the credibility of lay claims to knowledge have led to questions about how society ratifies, accepts or discredits expertise (Collins & Evans, 2002, 2007).

Collins and Evans (2002, 2007) argue that experiential knowledge or expertise in itself is not enough to justify an expert position within technical decision-making processes. Concerned that much of the previous sociological research, relating to lay knowledge and expertise, has effectively deconstructed the boundaries between experts and non-experts, Collins and Evans (2002, 2007) call for a re-examination of the way that expertise is selected and identified, advocating the development of a normative theory of expertise. Collins and Evans' (2002) model suggests that decisions will still be the domain of a 'core set' of expert decision-makers, rather the question to be answered is how a wider public will 'qualify' to be part of this core set. Hence, the normative theory of expertise, as proposed by Collins and Evans (2002, 2007) consists of three 'types' of qualifying expertise:

- 'Contributory expertise' entails having enough expertise to contribute to the science;
- 'Interactional expertise' means that one has '*enough expertise to interact with participants and carry out a sociological analysis.*' (Collins and Evans, 2002; 254);
- 'Referred expertise', which is expertise that one may have in a particular area that can be applied to another area.

For example, using the example of Epstein's study of HIV/AIDS activists, Collins and Evans (2002) point to the 'interactional expertise that the HIV/AIDS activists gained by engaging with the scientific discourse, granting them the label of 'non certified experts'. However, as Graham (2008) points out, the model provided by Collins and Evans (2002) is not concerned with a presumed democratic deficit, or presumption that expert decision-making processes become more transparent when they encapsulate a plurality of voices; rather it is a model that is based on a technocratic rationale for specific contributions that the public can make. Furthermore, the model proposed by Collins and Evans (2002) has been accused of being both vague (Martin, 2008) and reductionist (Jasanoff, 2003), and does not describe how decisions should be made about who is considered to have achieved expert

status. This could potentially reinforce traditional lay and expert demarcations. Moreover, Jasanoff (2003; 397) accuses Collins and Evans' (2002) model of focusing on a "*narrow formulation of the purposes of public participation in technically grounded decision-making*", and of going against the grain by seeking to limit rather than extend public participation. Jasanoff (2003) contends that rather than ask whether technical decisions should be based on narrowly defined expert advice or wider democratic processes, as Collins and Evans (2002) do, conceptualisations of expertise should be concerned with how to integrate different forms of knowledge.

Wynne (2003) has also provided a critique of Collins and Evans model. In particular, Wynne (2003) argues that in seeking to reflect on the legitimacy of experts, Collins and Evans (2002) have neglected the construction of expertise:

"I suggest instead that this multidimensional legitimacy problem is more about the institutional neglect of issues of public meaning, and the presumptive imposition of such meanings (and identities) on those publics and the public domain".
(Wynne, 2003; 402)

In other words, Wynne (2003) highlights the social construction and inherently political nature of science and expertise.

Two alternative models for public participation in decision-making are provided by Dyer (2004), following her research into the role of the lay member on Local Research Ethics Committees. The first model, 'extra scientific public participation', views the role of the public in decision-making as providing 'moral and social filters'. Here, public legitimacy for participation in decision-making is rooted in their personal experience. Dyer suggests that this model supports the idea that scientific facts can only be made by 'certified experts', yet that these facts can be balanced with the contribution of values from the public. One potential advantage of this model is that it potentially encourages lay people to be involved in research and technical decision-making settings irrespective of their knowledge of the techno-scientific world.

The second model suggested by Dyer (2004) is the 'scientifically engaged public participation' model. This model describes a *mobilised and scientifically literate* public involved in techno-scientific decision-making.

Unlike the first model, the credibility of the public is located in their ability to participate in a dialogue with techno-scientific experts and as such is similar to the 'interactional expertise' suggested by Collins & Evans (2002, 1007). Dyer suggests that this model recognises the 'value laden' nature of science and scientific decision-making, and public involvement in this sense is about challenging value judgements. Yet to do so, Dyer (2004) suggests that one must have attained the ability to converse in the technical discourse. Therefore, as with the critique of Collins and Evans (2002, 2007) model, Dyer's 'scientifically engaged' model potentially undermines the value of experiential expertise.

Whilst it is recognised that the boundaries separating these models are somewhat blurred (Collins & Evans, 2002; Dyer, 2004), what these models, and the previous section exploring the arguments concerned with experiential knowledge, highlight is the considerable complexity and ambiguity that surrounds the current health policy concerning public involvement in research. What contribution can (or do) the public make to research decision-making settings? Which members of the public are considered to have a credible role to play in research decision-making settings? What constitutes a credible voice in these settings? And what role should the public play in research decision-making settings? Such questions are worthy of further reflection and will be addressed within the aims and objectives of this thesis.

2.4.6. Summary of section two

In section two of the literature review, the wider sociological, political and theoretical debates that underpin the development of public involvement in research were considered. Firstly, it was argued that the work of Habermas, with particular reference to his ideas on the 'system' and the 'life-world', is pertinent to this thesis and provides a way to link micro and macro levels of society (Britten, 2008). The review outlined the literature pointing to a change in the relationship between science and society that suggests: a decline in public trust in expert systems (Beck, 1994, Giddens, 1990, 1991; Habermas, 1987); the growth of uncertainties associated with globalisation and the development of new technologies (Beck, 1994) and a perceived 'democratic deficit' (Barnes et al, 2006; Martin, 2008). As such it was suggested that forms of deliberative democracy, such as public involvement

in research may provide a remedy to these developments. However, the review highlighted how processes of participatory governance are far from straightforward and are tied up with notions of competence, legitimacy and constructions of credible expertise.

Taken together, section one and two of the literature highlight the necessity to explore the process of public involvement in research given the distinct claims that are made for involvement (as seen in section one) and the apparent complexity that surrounds these claims (as shown in section two). Therefore, having situated my research within the contemporary body of knowledge, in the next chapter I will provide details about the research that was conducted, restating my aims and objectives and outlining my approach to the study.

Chapter Three

Research Design and Methodology

3.1. Introduction

Having contextualised the thesis within the literature, this chapter will provide an account of the research design that was developed in order to explore the research questions. The chapter begins by restating the main research questions that are explored in this research. Following this, key methodological considerations affecting the type of data that would best answer the research questions will be outlined. This will involve a brief reflection on the 'quantitative versus qualitative research debate' and my rationale for selecting qualitative research. The chapter will then explore the research strategy and data collection methods that were chosen in order to best answer the research questions.

Prior to deciding to focus the study on the NCRN, some initial interviews were carried out with public and professionals involved in research decision-making settings from three health areas; mental health, dementia & neurodegenerative disease and cancer. The rationale informing this initial work will be provided, including the sample selection, the data collection methods and analysis techniques that were used. I will also detail how this initial work informed the main research.

Following this, I set out how the research was undertaken. I begin by detailing the sampling strategy that was used and the final sample that is included in this research. I then explore the practical process of undertaking this research, along with some of the methodological challenges that I faced. Issues of reflexivity, working with a lay advisor and ethical implications related to the research will also be covered. Furthermore, I will conclude the chapter by exploring some of the arguments concerning rigour in qualitative research and the ways in which I have attempted to strengthen my research in the light of these arguments.

3.2. Restating the research questions

As stated in chapter one, the broad topic area for the research was concerned with the reality and process of public involvement in health research.

The research questions addressed by this research cover the context of involvement, individual accounts and perceptions of involvement and the dynamics of involvement. Specifically, the research questions are:

- How do the 'involved public' and professionals rationalise and account for public involvement in health research?
- What roles do the public play in health research?
- How is the voice of the public integrated into health research spaces?
- What counts as credible expertise in research decision-making groups?

The chapter will now turn to outline key theoretical and methodological considerations in light of these questions.

3.3. Theoretical orientations and methodological considerations

A theoretical paradigm is a set of basic assumptions that in turn informs one's methodological decisions and consequently the methods that one uses to collect data (Crotty, 2003). There are different types of theoretical perspective, including:

- Positivism - with an emphasis on objectivity and verifiable knowledge claims.
- Interpretivism – encompassing hermeneutics, social constructionism and symbolic interactionism, with an emphasis on a constructionist approach to knowledge.

The interpretative framework forms the basis of much qualitative research. Drawing on the interpretivist tradition the social world is explored through the research participants' and the researcher's interpretations. It is impossible to be *value free* as understanding is continually negotiated

through interpretation (Richie & Lewis, 2003). I draw on Richie and Lewis' (2001) 'subtle realist' ontological stance in my perceptions about the social and natural world, in that I believe that there is a material world that exists independently of our interpretations, yet that what is perceived as reality is only known to us through our social constructions and interpretations. In many ways, I believe that this approach is consistent with, what one might label as, 'weak' social constructionism (Schwandt, 2000).

Due to the exploratory nature of the research questions, with their focus on interpreting multiple perspectives and meanings, and my own stance on the nature of the social world, a qualitative approach to the research was deemed to be most suitable. A number of distinctions between qualitative and quantitative approaches are presented in the literature. Firstly, qualitative research techniques are largely recognised as inductive in nature and are often used for exploring social settings and generating ideas and theories from the data (Denzin & Lincoln, 1998). In contrast, quantitative research methodologies are generally deductive in nature, used for testing a hypothesis or set of predefined ideas (Murphy et al, 1998). Secondly, research conducted within the qualitative approach pays great attention to the subjective nature of the data generated and the inextricable link between the researcher and the research participant (Mason, 2002). Within the qualitative paradigm, data are contextual and situated in personal accounts and constructions (Mason, 2002). Therefore, there is an emphasis on depth, detail and context within qualitative approaches. On the other hand, quantitative research methodologies tend to claim a degree of objectivity, and data are often reduced to numbers or the quantifiable.

Therefore, a qualitative approach to research was considered appropriate for a number of reasons. Firstly, my research questions are exploratory, rather than testing a defined hypothesis or predefined ideas. Secondly, I am interested in exploring depth and detail through multiple perspectives and participants' constructed accounts. A qualitative approach to the research enabled me to engage with the research participants in order that they actively reflect on their accounts, allowing me to probe and prompt for further meaning and reflection. This would not have been achievable using a quantitative approach. Thirdly, the emphasis within qualitative research on *processes* as well as *meanings* (Denzin and Lincoln 1998) was also seen to be particularly suited to my questions concerned with the roles that the

public play in research forums and the integration of patient/carer voices into these spaces.

3.4. Matching research methods to research aims

Having outlined my case for selecting a qualitative approach to the research, I now turn to the specific methods that I chose to collect my data. Within the qualitative tradition there are a number of research methods, or 'tools' that can be utilised for data collection. Observation, interviews, focus groups, documentary analysis, conversation analysis and biographical methods constitute the main methods available to the qualitative researcher (Mason, 2002; Richie & Lewis, 2003). My choice of methods was based on a number of reasons: the types of question that I was exploring and the data that I believed would best illuminate these; practicalities in terms of what was made available to me (time, resources, access); and personal preferences.

It became clear that due to my research topic of 'public involvement in research', which in itself a rather broad area of research, selecting specific examples or cases where involvement was occurring might provide me with one focussed way to address my research questions. In this way, the research draws its strength from the qualitative preference for depth and detail rather than quantitative concerns with generalisability. Selecting specific case studies is a common strategy in qualitative research that aims to understand *complex social phenomena* (Yin, 2003). Cases are selected on the basis that they illustrate a particular example of the phenomena under investigation (Yin, 2003) and as will be shown within this chapter, I selected case studies for my research that provided examples of public involvement at two different levels – local and national.

Furthermore, the research questions are all focussed on the study of a specific sub-culture, that of public involvement in research. Therefore, I felt that it was necessary to draw on aspects of the ethnographic tradition in order to best explore these research questions. In what follows I provide a brief exploration of the ethnographic tradition, reflecting on the key aspects of this research strategy that I hoped to bring to my own research.

3.4.1. Drawing on the ethnographic tradition

Ethnography, a technique associated with anthropology, has traditionally been concerned with the study of cultures and subcultures and the interpretation of phenomena through the accounts of those who experience them (Grbich, 1999; Taylor, 2002). Taken literally ethnography means 'a *description of folk*' (Boyle, 1994; 161). Ethnographic research aims to produce a deeper understanding of a particular culture or subculture through the values, accounts and perceptions of the participants within that particular case (Crotty, 2004). Ethnographic research is concerned with the depth and detail, seeking to understand how a particular group function, how certain social systems work or social dynamics have evolved. Data are generated 'in the field' with the researcher seeking to observe and record naturally occurring events (Denzin & Lincoln, 1998; Fielding, 2001). The ethnographic researcher aims to understand individual participants' 'situated accounts' in order to create a detailed picture of the field (Taylor, 2002).

"The ethnographic researcher is said to obtain an insider's view of society and so to understand other people's own worldview, instead of taking the outsider's perspective of the conventional scientist"
(Taylor, 2002).

Therefore, an ethnographic research approach is reliant on the researcher gaining access to the research field and typically becoming immersed in that field. An ethnographic approach demands that the researcher undertake detailed data collection in order to provide a comprehensive account of the field encountered. Geertz (1973) referred to this as 'thick description', a central feature of ethnographic work that sets it apart from other research techniques. A further aspect of ethnographic work is that it is *non-reductive* (Taylor, 2002) meaning that the diversity within the field of research is an essential element that is presented as a part of a holistic account. Larger chunks of data are reported rather than short sentences and snippets that can be seen as reductionist (Taylor, 2002).

Ethnography has been described as both a *process and a product* (Savage, 2000). The *process* is the specific technique that is applied and the *product* is the ethnographic written account (Savage, 2000). The process of ethnographic inquiry involves the use of multiple research methods in order to provide a holistic and contextual account. Observation (both participant

and non participant) is one of the most fundamental methods used. Observation tends to take an unstructured approach in order that the researcher is 'free' to pick up on the seemingly mundane, or 'taken for granted' instances, which may not be considered important at the initial stages of study conception, or that the participant might not consider to be important enough to mention in an interview (Becker & Geer, 1969). According to Mueke (1994), in classical ethnographies a key feature is the prolonged fieldwork, in which the researcher is a participant observer in the field continuously for at least a year.

One of the most well known examples of ethnography in health research is Goffman's (1961) 'Asylums'. Goffman undertook fieldwork over a year long period whilst acting as an assistant to the athletic director and claiming to be a student of recreation and community life. Conducting mainly covert participant observation of a mental health institution, Goffman (1961) used a symbolic interactionist perspective to reflect on the rules, rituals and forms of interaction within the institution. A further classic example of ethnography in health research can be found in Strong's (1979) work, 'The ceremonial order of the clinic'. This research was concerned with understanding the social rules that characterise the doctor/patient relationship. Strong observed 1120 consultations between health professionals, young patients and their parents over a three-and-a-half-year period. Strong and a fellow researcher collected the data using verbatim hand written notes and these notes were then taped and transcribed. Using the data from these observations, Strong (1979) was able to develop a 'typology of consultations', which provide the reader with a descriptive account of the different consultations observed, the similarities and differences between each of these and their typicality. Strong acknowledged the difficulties associated with observation as a primary method of data collection, such as the impact of the researcher upon the situation observed and the accuracy of note taking. However, he argued that as a method of data collection, observation has the advantage over interviews, as interviews are '*no guide to actual behaviour*' (Strong, 1979; 226). This clearly is a major strength of the ethnographic approach.

Notwithstanding this, interviews are also frequently utilised in ethnography. Interviews provide participants with the opportunity to reflect on their views, values, experiences, perceptions and observed behaviour. Interview data can help to elaborate on observations by providing participants' accounts of

social events, their actions and the actions of others. A third key method is documentary analysis where key documents relating to the field of research, such as minutes of meetings, can contribute towards understanding the case. Together these methods of data collection help to create a more complex and contextualised account of an organisation, group or community, providing both the emic (insider) and etic (outsider) perspective (Boyle, 1994). The three methods of data collection can complement each other. The interviews provide each participant's account of the research setting and their perception of the group dynamic, the observational data will provide an outsider's perspective on the research setting, the researcher's account of the group dynamic and provides the context to compare and contrast individual accounts with what is observed and build tacit knowledge. The documentary data can provide a historical context and background information on the organisational structure and culture.

In the next section I will explore some examples of how the ethnographic research approach has been applied in contemporary health settings.

3.4.2. Different types and examples of ethnography

Having so far outlined the key features of the ethnographic approach to research, in this section some examples of ethnographic research in health and social care will be explored. Within these fields, due to time and funding restrictions, ethnography has been used in a more targeted and succinct manner to the traditional applications that have previously been outlined. Muecke (1994) labels these ethnographies as 'focussed' or 'health science' ethnographies and states that they are commonly found in nursing research. The same commitment is paid to developing a detailed exploration of a particular group, however the amount of time spent in the field may be much reduced compared to that of classical ethnographic works (Muecke, 1994). Rather than a continual immersion within a particular subculture, observation is conducted at selected times and events over a set period of time (Muecke, 1994).

For example Griffiths (2002) conducted ethnography into the use of humour amongst two community mental health teams. Data were collected over a 12-month period, which entailed the researcher attending weekly team meetings and conducting unstructured interviews with team members. The

team meetings and the interviews were audio taped and transcribed verbatim. Audio recording of observational sessions is not always considered an appropriate approach due to difficulties associated with ethical approval, ability to distinguish between multiple voices on the recordings, and the time taken to transcribe this data. However, due to the specific approach that Griffiths (2002) was taking to analyse the data - conversation analysis - in this instance it was appropriate to audio record the data. In a different health services ethnography, Fudge et al (2008) explored service user involvement in the development of stroke services. Fudge et al (2008) used participant observation at set times to observe specific meetings, documentary analysis and semi-structured interviews over a two-year data collection period. Fudge et al (2008) recorded the observational data using handwritten notes and also maintaining a reflexive diary. The interviews were tape recorded and transcribed verbatim. All data were analysed for key themes and patterns. The resulting ethnographic account 'provides a detailed reflection of service user involvement in stroke services referring directly to extracts of data from the reflexive diary, the interviews and the meeting notes.

A further ethnography worth mentioning was one carried out by Atkinson (1995). Undertaking fieldwork in a US hospital over a ten-week period, Atkinson followed the work of three clinical fellows working in a haematology-oncology department, in order to look at the interaction between medical professionals and the construction and application of medical language. The ethnographic account produced is richly descriptive that both sets the scene and draws the reader in, as a work of fiction may do, yet also critically engages with the issues and themes arising from the data.

Having outlined some examples of how ethnography has been applied in a variety of contemporary health research settings, the next section will turn to reflect on some of the criticisms that are targeted at the ethnographic approach.

3.4.3. Critiques of ethnography

As with any methodology ethnography has its limitations and critiques. One of the key criticisms concerns the degree of subjectivity that is embedded in ethnographic work, which is a criticism that is made of qualitative research

more broadly. Subjectivity is addressed by defenders of ethnographic research and the qualitative tradition more widely, as an unavoidable, and moreover necessary, part of engaging with data in a naturalistic setting. As the researcher is the research instrument and is engaged with the research field in order to gain insight and understanding of complex phenomenon on its own terms (Guba & Lincoln, 1981) subjectivity is an inherent part of the account that is constructed and is not necessarily a negative aspect of the technique.

One way of addressing this criticism is by maintaining reflexive practices throughout the research process, acknowledging one's personal perspective, how themes are generated from data and how conclusions have been arrived at (Atkinson, 1990). This is often done through the use of a reflexive diary. Reflexive practice was followed throughout this research in the form of both an ongoing research diary, which included general field notes, personal reflections and daily points of interest. In addition, prior to beginning data collection a situational analysis was carried out which outlined my motivation for undertaking the research, prior experience and assumptions. A reflexive account of the research process is provided at the end of this chapter and in chapter ten.

A further criticism aimed at ethnography, and again other qualitative research, concerns the generalisability of ethnographic research findings (Savage, 2000). The ethnographic researcher does not make claims to generalisation, rather the ethnographic account is a product of the way in which the researcher engaged with a particular research field and constructed an account for the data that was generated (Hammersely, 1992; Taylor, 2002). It is the depth of the account that is useful and from this depth parallels to other research settings might be drawn (Stake, 1998). Other criticisms include the labour intensive nature of ethnographic research (Savage, 2000). However, this can be overcome by undertaking a 'focused' or 'health sciences' ethnography as proposed by Muecke (1994) and illustrated with the examples in the previous section.

Despite acknowledging criticisms, given the types of question that the research sought to explore, with their focus on understanding meaning, motivations, relationships and dynamics, I felt that certain aspects of the ethnographic process were indeed relevant for the research. The methods

section will detail the particular methods that I have used for this research, but my overall aim was to follow the ethnographic tradition, capturing depth and detail and exploring the research questions through the use of multiple methods.

I will now explain how I selected the sample for the research, turning first to some initial interviews that were conducted in order to explore the field. After this, I will explain in more detail my choice of data collection methods and how these methods were practically applied.

3.5. Initial Exploratory Interviews

Before turning to the main research stage, the initial exploratory work informing the research sample and case study selection will be outlined. The literature review highlighted the wide range of areas in which the public are involved in health research. As the research questions are specifically focussed on exploring if, and how, the voice of the public are integrated into research decision-making settings, the initial stage of the research set out to find out the different contexts in which this took place. Most importantly the initial stage was necessary in order to identify the most appropriate areas for more detailed ethnographic research.

During the initial stage I was interested in exploring the scope and range of involvement in health research, through public and professional accounts. The UK Clinical Research Collaboration (UKCRC) was chosen as the sampling population for the research. The reasons for selecting the UKCRC as the sample population are as follows:

- The UKCRC provides the most comprehensive infrastructure for clinical research conducted in the UK, bringing together clinical research in the National Health Service, academia, patient groups and organisations, research funders and charities, regulatory bodies, industry and Royal Colleges (UKCRC, 2008).
- Furthermore, as part of the UKCRC there is an established network of research comprising seven disease specific networks: Cancer, Mental Health, Stroke, Diabetes, Dementia and Neurodegenerative Diseases, Primary Care and Medicines for Children. As part of this, each network has a database of the clinical research that has been conducted, and

the key contact names for each project. Therefore, it was felt that a broad scope of health areas was comprehensively covered and a wide range of professionals could be contacted.

- As the NHS is a partner organisation the UKCRC is subject to the Department of Health policy for public involvement in research. As part of this, each of the seven disease networks is developing their approach to public involvement in research. It was therefore felt that within these networks there would be a good opportunity to select case studies to undertake the ethnographic research.

From the seven disease specific areas, the exploratory sample was narrowed down to the National Cancer Research Network (NCRN), the Mental Health Network (MHN) and the Dementia and Neurodegenerative Disease Network (DeNDRoN). The reasons for this choice were: firstly a review of the literature led me to believe that these groups had the most developed strategies for public involvement in research; each of these networks had developed a strategy towards involving the public in research and would therefore have case studies that could be selected for the main research stage; and because the range of public involvement in research across these three groups was felt to be fairly diverse. Within the MHN service user led research is increasingly common, the NCRN has a history of working with professionals in collaborative research, whilst DeNDRoN is a relatively recent group with a greater emphasis on carer involvement in research. On this basis it was considered that these three groups would provide a range of perspectives and experiences. I will turn to explore the data collection methods used for this research.

3.5.1. Choice of data collection methods

I chose to conduct semi-structured interviews for the exploratory work, using a combination of telephone and face-to-face interviews. My choice of the interview as a data collection method was based on its suitability for the research questions, with their focus on exploring participants accounts of roles, relationships and experiences of involvement with participants' asked to provide practical examples throughout the interview. Using semi-structured interviews meant that I was able to follow a broad topic guide in order to explore certain themes and ask particular questions of every

participant, but providing flexibility within the interview to develop and explore new and emerging ideas introduced by the participant.

For the interviews, a topic guide was derived from the literature, from discussion with the supervisory panel and in collaboration with my lay advisor. The interview guide was piloted with two individuals in the field prior to data collection. The piloting exercise was extremely beneficial in helping to refine the topic guide and provide some practical experience of conducting interviews and build up my confidence. The interview aimed to cover experiences of and attitudes towards public involvement in research, reflections on the policy of public involvement in research, consideration of the social dynamics of involving the public in research, motivations for involving the public in research/becoming involved in research and the role and contribution of the public in research (see appendix B). Further discussion about the use of interviews to collect qualitative data can be found in section 3.6.2.

A combination of face-to-face and telephone interviews were used. This was due to restrictions in time, available resources, geographical location and also participants' preference. Telephone and face-to-face interviews both presented benefits and drawbacks. Telephone interviews are a relatively cost effective way of collecting qualitative data, they allow the interviewer to follow their topic guide, without having to maintain eye contact, and may also appeal to participants' who want to preserve a level of anonymity, perhaps yielding greater openness and ease (Sturges & Hanrahan, 2004). However, telephone interviews can also present potential problems associated with the reduction of social cues, which may prevent a natural dialogue and free flowing conversation to develop (Opdenakker, 2006). Without the visual aide that a face-to-face interview provides it can be difficult for the interviewer to assume when a participant has come to a natural end on a point that they are making, or taking pause for thought.

Face-to-face interviews have the potential benefit of creating a greater sense of rapport between the interviewer and the participant as they allow eye contact and the use of body language. These can be valuable mechanisms for both maintaining a dialogue and a sense of how the participant may *feel* about what they are saying (Opdenakker, 2006). During some face-to-face interviews following an interview guide was difficult because of a desire to

maintain eye contact and this resulted in some face-to-face interviews *going off track* on some occasions. Whilst the benefits and drawbacks have been explored, the data collected using both of these techniques were found to be equally rich and informative, with no apparent differences based on the use of each method.

3.5.2. Sampling and recruitment

Whilst my interview sample was guided by the data and emerging themes, I had a target interview sample size of 30 participants for this stage of the research, with an ideal sample of 10 participants from each of the 3 networks; 5 professionals and 5 members of the public. I felt that this would allow me to engage with a range of views. My final sample of 28 participants for this initial exploratory stage can be seen in table 3.1.

Table 3.1 Exploratory Interview Stage Sample

Network	Professional Participants Recruited (target)	Patient/Carer Participants Recruited (target)
Cancer	4(5)	8(5)
Mental Health	4(5)	2(5)
DeNDRoN	5(5) plus informal conversation with PPI lead	5(5)
Total Numbers	13	15

Each of the three networks has a database of projects registered, with a lead researcher and contact email listed. In order to recruit the professional participants I sent an email invitation to take part in an interview to each professional listed. Within the NCRN 140 emails were sent, 31 to DeNDRoN professionals and 90 within the MHN. Following a poor response from DeNDRoN and the MHN I contacted the named Study Development Managers and asked if they could suggest researchers within the network. From this I received a further 2 positive responses for the DeNDRoN network but no response from the MHN.

I also contacted the three Patient and Public Involvement (PPI) leads from the networks and invited them to take part in an interview. The PPI leads from the NCRN and DeNDRoN responded. I arranged an interview with the

PPI lead from the Cancer Network, however due to difficulties with schedules I only managed to have an informal conversation with the PPI lead from DeNDRoN.

For the recruitment of the public participants I contacted the PPI leads and asked if they would forward my interview invitation onto their patient/carer members and groups. However, whilst I received a positive response from both the NCRN and DeNDRoN PPI leads, after repeated attempts at contact, the MHN PPI lead never responded to me. Therefore, in order to recruit mental health service users, I asked the professionals within the mental health network that I interviewed if they could provide me with the details of the service users or service user groups that they had worked with, effectively resulting in a snowball sample.

The entire interview sample in the exploratory stage reflects the sum total of replies that I received. The only exception to this was the cancer patient/carer group where I received 13 positive responses to take part in an interview and I ended up interviewing 8 of these people based on our ability to arrange an interview at a suitable time and in order to reflect as much diversity within the interview group as possible.

I only received one negative response to my invitation to take part in an interview. This came from a professional within the MHN who replied that they had *"taken advice from our Departmental Head and unfortunately we are unable to help you at this time."* It was partly for this reason that my main research was narrowed to the NCRN. This will be explored in more detail in section 3.5.4.

3.5.3. Conducting the interviews

The interviews were conducted between November 2007 and January 2008. Prior to beginning the interviews I reminded the participant of the research project aims to ensure that they were comfortable proceeding and asked if they were agreeable to the interview being audio recorded (of which all were). A greater period of time was spent on general conversation during the face-to-face interviews. I felt that this often helped to create a relaxed and informal environment. In contrast the telephone interviews were generally more focussed and direct, with less time spent on informal conversation and

building rapport. Despite this I feel that there is little difference in the quality of data and clearly some participants' prefer one technique over another.

The interviews lasted between 30 minutes and 1 hour and 30 minutes, with an average length of one hour. All interviews were digitally recorded and transcribed verbatim by the researcher.

The data from the initial exploratory stage were analysed using an interpretative thematic approach to analysis, as proposed by Seale (2004), based on the key principles of open coding, categorisation, theme generation. This is explored in further detail in section 3.7.

I used the qualitative data software package, QSR NVivo (2002) to manage the data. I found this software to be particularly effective in providing a central place to store and access the transcripts during my ongoing analysis. I also found the coding or 'node' function extremely practical as it allowed tentative codes to be assigned and then later changed if necessary, code descriptions to be stored and the use of memos that could be 'attached' to certain parts of the interview transcript were also extremely helpful.

3.5.4. Implications of the exploratory work: informing the case study selection

Following the exploratory interviews, it was decided that the NCRN would provide the most suitable site for the main ethnographic research. The findings from the initial interviews revealed a clear theoretical case for selecting the NCRN, as well as some practical implications. In terms of the broad theoretical framework underpinning the research, the findings illustrated that the NCRN provided an example of a large umbrella organisation where public involvement could be found at national/strategic level and at a local level. More specifically, in comparison to the other two networks, the findings revealed how the NCRN had clear processes in place for public involvement in their national research decision-making spaces – Clinical Studies Groups (CSGs) (See figure 4.1 on page 113). Therefore, in terms of exploring the dynamics of involvement and the integration of the public into research decision-making settings, using applied ethnographic research, it was felt that the NCRN provided the most appropriate setting in which to explore this.

Furthermore, I felt that it would be fruitful to reflect on the research questions in terms of the similarities and differences that may be apparent between national and local cases of involvement within one larger overarching organisation. In particular, I was interested in exploring the potential impact of structural arrangements (i.e. the differences between local and national levels) on the way that the patient/carer voice is integrated into research decision-making spaces.

In terms of the practical arguments for selecting the NCRN, as I have already mentioned, it was clear that access to the MHN, with regards to selecting cases for ethnographic work was not going to be possible. Furthermore, it was felt that DeNDRoN was not developed enough in order to provide a range of cases for the ethnographic work.

In addition, key individuals from the NCRN had proven to be extremely helpful to me throughout the initial research stage and were keen to assist me by providing contact names and suggestions. As such access to specific cases for the ethnographic work was far easier with the assistance of a known and respected figure, rather than approaching a group blind. Following discussions with the PPI lead from the NCRN, I was introduced to the organiser of the Clinical Studies Groups, the main groups where the public are involved at national/strategic level.

With regards to researching involvement at the local level, I had developed contacts within a well-established local group, through my supervisory support, some previous research and as a result of the exploratory work. Furthermore, the local group had asked if I would provide some facilitation and administration work for them on a part time basis and were happy that I could do this whilst also researching them as my local case study. This enabled me to become a participant observer within the Local Research Panel (LRP). Therefore, in terms of access, the NCRN was a sensible choice.

Consequently, the main research questions are explored within the context of the NCRN. As such the data from the 12 interviews conducted with public and professional participants within the NCRN for the exploratory work have been included as part of the main research.

Whilst the primary aim of the initial exploratory phase was to locate a suitable sampling framework for the ethnographic work, the data from the 16 interviews conducted with the public and professionals from the MHN and DeNDRoN will be provided as an appendix (appendix A). The data generated from these 16 interviews provide additional accounts of involvement that are useful in terms of exploring findings that may be unique to the cancer network and those which may be generalised outside of the cancer network.

Chapter four will provide an account of each of the case studies selected for the research. This will include the context and background, issues of access, scope of data collected and my personal reflections about each group. I will now turn to the main methods used for the primary focus of the thesis.

3.6. Main Research Methods

The following section will provide an exploration of the data collection methods used within each of the case studies. For each method chosen, I will explore some of the theoretical and methodological implications that are discussed in the literature and following this I will provide an account detailing my practical application of the method within the case studies.

3.6.1. Observation

In terms of the research questions, the observational work was important in order to explore group dynamics, the roles that participants play, the interaction between group members and specifically how the public voice was integrated into each case study. Observational methods enable the researcher to “*capture phenomena in its own terms*” (Guba & Lincoln, 1981; 193). Observation can provide the researcher with a ‘check’ on what people say they do during an interview and what they actually do in practice (Mulhall, 2003). Observational methods can take a number of forms depending on the degree to which the observer is a participant in the social setting, whether the researcher follows a structured or unstructured method of collecting data and if they are overtly or covertly observing.

Gold (1958) classified observer roles into four main types:

- Complete participant
- Participant-as-observer

- Observer-as-participant
- Complete observer

The complete participant role is typically covert, with the researcher's real identity concealed from the rest of the case group members. Holdaway's (1983) ethnography of the British police force is an example of the complete participant role, as is Goffman's (1961) ethnography of a mental health institution. However, operating as a complete participant has ethical implications, as the subjects of the research are not informed of the researcher's true intentions. For this reason, I chose not to adopt this role.

The participant-as-observer role entails the researcher closely engaging with the research setting or case, as with the complete participant, but doing so in an overt manner with the members of the group aware of the researcher's identity and research aims (Bryman, 2001). The observer-as-participant involves the researcher acting primarily as an observer with limited opportunity for participation in the research setting. This could entail observation of meetings, or situations whereby participation would interrupt the naturally occurring order (Bryman, 2001). Finally the complete observer role is one in which the researcher does not interact at all with the members of the research setting. For this research I used the roles of both participant-as-observer, or participant observation (for the LRP) and observer-as-participant, or non-participant observation (for the CSGs and subgroup). I found the former approach used with the LRP, resulted in my access to rich data that I would not have been privy to if I wasn't there in a participant role. However, there were also some ethical implications associated with this role, which are outlined in section 3.10. Using a non-participant approach with the CSGs was appropriate for these groups and meant that the ethical implications were far reduced.

During my participant and non-participant observation I used an unstructured approach to collecting data. Unstructured observation differs from structured observation, in that checklists and pre-coded categories are used to guide the observation (Emerson, 1981 in Murphy et al, 1998). Observers using an unstructured approach may have some assumptions about what they might observe however the aim is to enter the research setting with as few preconceptions as possible (Mulhall, 2003). As observation is conducted over a period of time, a 'progressive focus' may

occur whereby the researcher starts to look for specific phenomena in accordance with prior observations (Murphy et al, 1998). Whilst I had formed a number of assumptions based on the prior reading and research that I had undertaken (see section 3.12: *Reflexivity*), and some key questions and specific areas that I wanted to look at to cover my main research objectives, I was essentially entering the research field with a relatively limited perspective about what I would observe.

Non-participant observation of the Clinical Studies Groups and Subgroup

Between May and September 2008, I observed meetings of five CSGs. I completed two sessions of observation in February and November 2008 with the subgroup. Taking on a non-participant role my interaction with this group was limited to introducing myself to the group, reminding them of my role in the meeting, and some limited interaction with members (primarily patient/carer members) during coffee and lunch breaks. For the majority of the time I observed the meetings silently from the place that I was given around the meeting table.

During the meetings I would make written field notes with pen and paper. As Fielding (2001; 152) notes:

"The production of fieldnotes is the observer's raison d'etre: if you do not record what happens you might as well not be in the setting".

Field notes may be written accounts of some observation, personal reflections on the research process, events that have been observed, or concerning individuals within the case, or they may be initial themes or ideas that are generated during the research process. Generally they contain a running description of situations and events that have been observed (Fielding, 2001; Lofland, 2004). Scene setting is also an important aspect of the field notes, often including maps, or diagrams of where people are located, the room layout etc. Describing particular tasks that are undertaken and who is doing them is also important (Geertz, 2004). My notes would include a diagram of who was in the meeting room and where they were sitting, the immediate environment, sections of commentary and specific comments made by group members, reflections on interaction, body language, members' contributions and my overall impressions of the group.

As close to the end of each meeting I would write up the field notes in full including additional thoughts or associations with theoretical perspectives. This was often done on the train journey home, or that evening. A reflective account of each meeting was typed up and provided a descriptive account of the session of observation. Early on I had decided against the use of a digital recording of the meetings. My reasons for this included: the potential that this might dissuade groups from volunteering to be a case study; the vast amount of data that would be produced from an 8 hour meeting; plus issues of the quality of recording that could be made in such large meetings and how I would distinguish between participants. Therefore, I relied solely on my hand written field notes. Furthermore, at the end of each session of observation in addition to completing a fuller written log of my field notes, I also wrote a narrative description of the case study in question and my time observing them.

Observation of local research panel

My role within the LRP was as a participant-as-observer. The use of the term *participant* emphasises that, unlike some other observational methods where an element of detachment is maintained, the participant observer is just that – a participant in the research case, often taking part in the activities of the group. As Denzin (1970; 187) states "*a central assumption of participant observation is that the investigator shares as intimately as possible in the life and activities of those he is studying.*" As I was working with the panel on a weekly basis I was fully engaged in their weekly activities and interaction. From March 2008 through to March 2009 I collected field data on the LRP. During this time I attended quarterly meetings with the group members, research sub group meetings with selected members, executive group meetings and 1:1 meetings with particular members. I was in regular email and telephone contact with group members, in particular the Chair. I was invited by the Chair to attend a number of larger meetings with other organisations, including the Primary Care Trusts in the local area, other local research panels and a large conference. Further details on the extent of my observational data can be found in chapter 4: 'Introduction to the case studies'.

I believe that there were many benefits from conducting such close work through immersion in the research field. Most fundamentally, I felt I was able

to gain a greater understanding of how meanings were constructed within the group, the subtle operation with the group, whilst also understanding different member characteristics, relationships and group dynamics. I would agree with Fielding (2001) that participant observation is particularly useful for understanding "*the rules which govern the relationships and interactions within the settings studied to discern the patterns in the behaviour of members of that setting*" (Fielding, 1993:157 in Murphy et al 1998).

As with the CSGs, I rejected the possibility of digitally recording my observation within the LRP. Again, this was due to the reasons that I have already stated above, including the vast amount of data that would be produced from the meetings and the quality of digital recordings when there are multiple participants present. Throughout the data collection period I maintained a research diary. Here I consistently recorded and maintained my field notes. These included notes from sessions of observation, any particular events, or interaction/communication with members that I thought may be pertinent, plus my on going reflections on the group and emerging theoretical frameworks.

In the next section I explore my use of interviews as a further source of data collected for this research.

3.6.2. Interviews

Interviews are a dialogue, a 'conversation with a purpose' (Erlandson et al, 1993). They allow for reflection, introspection and in-depth discussion. Interviews help to provide the *emic perspective*, or insider viewpoint (Boyle, 1994). Interviews and observational data are complementary to one another and together help to provide a contextual account reflecting on both the insider account and the *etic*, or outsider (the researcher) perspective (Boyle, 1994). Interviews within ethnographic work can consist of both the 'informal' questioning and querying of participants throughout the period of participant observation and the more 'formal' types of interview whereby the researcher arranges to specifically interview a participant at a given time. Whilst I conducted some, what may be classed as, 'informal interviews' (in particular with the local research panel), in the main I relied on formal interview techniques and data.

Interviews were conducted in order to explore individuals' accounts of involvement and their reflections of working within the various case study groups. In terms of the research questions, the interviews were necessary in order to explore public and professional rationalisations of involvement. They were also particularly important in terms of comparing my perception of how a case study group worked, based on my observations, with participant's own perceptions. Furthermore, interview and observational data are complementary in terms of exploring individual rationalisations of involvement in comparison with their observed actions.

The interviews were semi-structured in nature. A topic guide was constructed based on the main research questions, themes arising from the initial research stage interviews, questions that emerged from the observation and discussions with supervisors and the lay advisor. Whilst a topic guide was used, the interviews were flexible and provided the opportunity for participants to direct the dialogue, often discussing issues that I may not have considered. Probes and prompts were used as methods of drawing out fuller answers from participants. In reflecting back on the interviews my probing skills improved as I became much more confident in the role of interviewer and my knowledge of the field increased. For example, when I reflected on some of the earlier transcripts I could identify areas that were worthy of further questioning that I did not follow during the interview. However, I see this as part of the ongoing process that I have gone through and believe that interview skills can only be honed through experience.

As with the initial research stage, I used a combination of face-to-face and telephone interviews, dependent on practical resources and the participant's choice. I found that due to the nature of some of my participants, i.e. busy professionals who were often unwilling or unable to give their time for an interview, I had to be fairly pragmatic and seize opportunities to interview as they arose. For example, at the request of one participant (professional member of one of the clinical studies groups), I conducted a telephone interview as he travelled between his working locations. At times this process was frustrating (especially as the telephone conversation was cut off three times due to bad reception) but the data was extremely important and it was necessary that I was able to adapt in order to access particular people.

During the interviews I jotted down notes and they were also audio-taped, with the permission of the participant. Following the interviews I transcribed the audio data verbatim and included any notes on my thoughts, feelings and reflections at the end of the document. These included; notes on body language, my general impressions and any ideas that may have arisen from the interviews.

Rapport is a key element of gaining interview data that provides an insight into the participant's perspective. According to Fontana & Frey (2000; 655):

"...the interviewer must be able to take the role of the respondents and attempt to see the situation from their viewpoint, rather than superimpose his or her world of academia and preconceptions on them."

I found that establishing rapport was easier with the local research panel, as I became immersed in the work of the group and built up relationships of trust with the group members. However, as Fontana and Frey (2000) point out, whilst this closeness with a group may help in establishing an insiders point of view and a better understanding of the group, the downside is that the researcher can forget or forfeit their research aims and objectives, or become too close to the group. I found that this was sometimes the case with the local research panel and this is an issue that I discuss in section 3.10 during my reflections about working with the group.

Interviews were also conducted with members of the CSGs, the CSG subgroup and the local research panel. For the CSGs and the CSG subgroup, I asked my contact within the CSG secretariat to forward an email inviting all members to take part in an interview. I arranged an interview with each person who responded. For the local research panel, all members were invited to take part in a formal interview at various points throughout the data collection period. Due to difficulties in arranging interviews with members (work/family commitments, ill health) and because many members preferred to talk to me in an informal interview setting, formal interviews were conducted with four panel members, the panel secretary and two researchers who had worked with panel members on research projects (these include those from the initial interview stage). Table 5.1 on page 127 provides the details on all of the interview participants for the case studies.

As with the interviews from the first stage, the main research interviews were a combination of face-to-face and telephone interviews. They lasted between 30 minutes and two hours with the average interview lasting approximately 45 minutes. The final number of interviews conducted can be found in table 3.2.

Table 3.2: Total interviews conducted

Case Type	Total Interviews conducted for the case
Clinical Studies Groups ¹	14 (6 consumer members and 8 professional members)
Clinical Studies Subgroup	4 (2 consumer members and 2 professional members)
Local Research Panel	7 (4 consumer members and 3 professional members)

3.6.3. Documents

Key documents relating to each case were collected wherever possible. These included minutes of previous meetings, group newsletters, emails, person specifications for job roles etc. The specific documents collected for each case will be outlined in chapter four. The next section will outline how the data were analysed.

3.7. Data analysis

Data analysis was an iterative process that was conducted alongside data collection. For example, as I was undertaking the observational data collection, I was continually reflecting and refining ideas, assigning tentative codes to particular datasets and notes. Daily events and encounters in the field would impact on my reflections, the analysis and questions. New interviews were also being conducted in parallel with analysing existing interview transcripts. Therefore, discussing the analysis of the data as a standalone section is a superficial imposition, yet necessary for the purposes of attempting to explain the process that I followed.

As I have previously noted, the interviews were all audio recorded. I completed verbatim transcripts of each digital interview recording. This was

¹ In addition interviews were conducted with two consumer members and one professional member of other Clinical Studies Groups and the PPI lead/Consumer Liaison Lead as part of the initial exploratory work and with a member of the CSG secretariat.

an extremely long and arduous process, taking me about 3 hours transcription work for every 1 hour of audio tape and amounting to over 100 hours spent transcribing. However, I believe that there were many benefits of completing the transcription myself rather than employing someone else to do this task, not to mention the significant cost implications. For example, listening to the audio data, whilst completing the transcription, meant that I was constantly immersed in my data. I was able to reflect on themes, codes and nuances whilst transcribing, and I found that the audio data had a greater impact on me than just reading through the transcripts.

For both the interview data and the observational data (in the form of field notes, written accounts and reflexive journals) an interpretative thematic approach to analysis, as proposed by Seale (2004), was used. This approach is based on the key principles of open coding, categorisation and theme generation. I chose this approach as it was consistent with the overall methodology, with a focus on interpretation and allowing the multiple perspectives of the research participants to be heard. This approach also provides a systematic, step-by-step method of analysing data (Seale, 2004). In order to analyse my data I used a combination of paper and coloured pens – marking hard copies of transcripts and field notes – plus electronic coding of word documents. I found that I enjoyed the pen and paper process most, however as my data grew, the electronic process was the one that I became most reliant on as it was a more practical choice. I will explore this in more detail further on in this section.

The actual analysis process involved reading through each transcript, my field notes and my reflexive journals and conducting initial open coding on a line-by-line basis, ensuring that all data are considered and reflected on. My choice of coding was largely guided by my research questions, however I tried not to be too prescriptive so that data and themes may emerge that I had not previously considered. After this initial stage I had a list of approximately 80 individual codes. During the initial open coding process, and throughout the data collection process, I also made theoretical memos which recorded my initial thoughts and reflections on the data, my reasons for assigning particular codes and my thoughts on emerging theoretical frameworks. As the number of open codes became quite large, maintaining a log with a description of each code and my rationale for coding certain chunks of data became increasingly important. Once I had completed the

first open coding stage, my next challenge was to reduce the data even further. Therefore, I re-read the data and undertook more selective and detailed coding. During this stage I began to make links and comparisons between themes, participants and with the wider literature as a fuller account for the data began to emerge. The documents that I had collected were analysed for their content, in relation to my research questions and they were related to the emerging data themes and overarching frameworks. Furthermore, I reflected on the themes both within and between cases, searching for similarities and inconsistencies, which could help me explore my research questions.

The analysis process and the task of reducing the data continued until I felt that I had established some logical arguments and provided an adequate exploration of my research questions. Of course deciding when to end my analysis was not straightforward, and I continued to reflect on the data as I was writing up my findings chapters, often returning to the original texts, re-reading them and refining my thoughts. Once I felt that I had reduced the data to a coherent set of arguments that explored my research questions, I tested these ideas out with my supervisors. One supervisor conducted a quick analysis of a small number of the transcripts and we compared and contrasted our interpretation and key findings. This exercise was useful in building my confidence in the approach that I had taken and the findings that I had arrived at. However, the findings that are presented are essentially accounts that are subject to the choices that I have made regarding the initial investigation, questions, interpretation and presentation.

As with the initial research stage, I continued to use the qualitative data software package, QSR NVivo to manage the data. Much of the literature points to potential issues associated with the use of software to assist with the process of qualitative data analysis (Richie & Lewis, 2003). The key concern appears to be that the software is seen as a tool for conducting the analysis, replacing the role of the researcher in becoming immersed in the analytic process (Richie & Lewis, 2003). I did not find this argument to be an issue with my analysis. Whilst the software was extremely useful as a central storage point for the data and allowing me to readily assign and delete codes, I still found that I would simultaneously return to printing out my transcripts and accounts and would make notes and memos by hand. Thus I

was still fully immersed in the data and the software was used as an additional storage and data retrieval mechanism.

3.8. Ensuring rigour in research

The following sections will detail some of the decisions that I made in order to ensure the rigour of the research. Issues of rigour are common to all research. If the rigour of the research is in doubt then the findings may be open to question. When discussing rigour, some qualitative researchers talk of validity and reliability, terms that are most widely associated with the natural sciences (Richie & Lewis, 2003). However, due to *"the very different epistemological basis of qualitative research, there are real concerns about whether the same concepts have any value in determining the quality or sustainability of qualitative evidence"* (Richie & Lewis, 2003; 270). Consequently, a number of different criteria for assessing qualitative research have been proposed. Erlandson et al (1993) propose four criteria to assess rigour in qualitative research:

- **Credibility** – the degree of confidence in the 'truth' of the research findings
- **Transferability** – the degree to which the findings can be transferred to other settings
- **Dependability** – the degree to which the research makes an account for decisions made, influences on decisions and the effect that these may have on the research
- **Confirmability** – the degree to which the research findings may be confirmed by others

Barbour (2001) has argued strongly against the use of such criteria, claiming that they can result in nothing more than a 'prescriptive' checklist. Barbour (2001) claims that the use of such a checklist can often draw the researchers' and readers' attention away from the interpretative paradigm that qualitative research is often located within. Therefore, it is important that such criteria are used in addition to sound qualitative research, rather than as proof of quality:

"They can strengthen the rigour of qualitative research only if they are embedded in a broad understanding of qualitative research design and data analysis" (Barbour, 2001; 1117).

With Barbour's (2001) comments in mind I considered the four criteria suggested by Erlandson et al (1993). Each criterion is listed below with details on how I sought to address them within the research.

3.8.1. Credibility

The credibility of the research is strengthened in a number of ways. Firstly, through the use of multiple data sources, drawn from observation, interviews and documents in order to provide a holistic, contextual account (Boyle, 1994).

Secondly, a lay advisor was involved in the discussions and decisions throughout the project. This included advice about the types of question to ask, particular things to look for during observation, and comments and discussions about key themes arising from the research.

Thirdly, in analysing the data, initial ideas and thematic frameworks were considered between cases, using the constant comparative method, during which I looked for confirmatory or refuting evidence (Silverman, 2001). Furthermore, the analysis was carried out in close collaboration with one supervisor. A selection of transcripts were independently analysed by the supervisor and themes and ideas discussed. The resulting findings were taken to my supervisory meetings for further discussion and consideration with the whole supervisory panel.

Furthermore, when presenting the findings, I will provide the original data, which will allow the reader to consider both the interpretation and the original source (Murphy et al, 1998).

Lastly, I maintained a reflexive diary throughout the research. This was useful in providing reflections on why situations and scenarios were being constructed in particular ways and for reminding me about how I felt at certain stages throughout the research process and of any influences on my opinion.

3.8.2. Transferability

The research is located within the Interpretivist paradigm, and as such I acknowledge that it is a co-construction between myself, the research participants and the research field. Accordingly, the generalisability or transferability of the research is limited. As Taylor (2002; 3) states the purpose is to "*produce situated knowledge rather than universals and to capture the detail of social life rather than abstracting from this detail to produce reductive models.*" Thick description, as developed in anthropology by Geertz (1973), whereby the context and full descriptions are provided to enable the reader to draw meaningful conclusion, will also be provided in the findings. The use of such thick description may enable the reader to relate to certain elements within the findings or make some comparisons between the findings and other research fields (Stake, 1998).

Purposive sampling is a further strategy used to enhance transferability (Erlandson et al 1993). Purposive sampling is concerned with maximising the scope of the research, seeking out typical and deviant cases. I attempted to address this during the main research stage by seeking to cover the three tiers of public involvement in the NCRN: the national formal level (in the form of the CSGs), the national informal level (in the form of the CSG subgroup) and the local level (The LRP), and also drawing on a wide range of voices within these cases, from a variety of professional and consumer members.

3.8.3. Dependability and confirmability

In order to strengthen the dependability and confirmability of the research two primary approaches were taken. Firstly, the qualitative data management package NVIVO was used to store and manage the data. The data were coded and analysis decisions recorded within this software through the use of analytical memos, labels and descriptions of codes, initial grouping of codes and eventual theme building. This essentially provided a central point through which my analysis process may be tracked.

Secondly, a reflective diary was maintained throughout the research period. This diary provided reflection on some of the key decisions that were taken,

events that I encountered and my interpretations of these events which may impact on the final research product.

3.9. Role of the lay advisor

Throughout the life of the project, from the initial ideas generation and conception stages, through to the data collection, analysis and dissemination of the research, I have sought lay advice wherever possible. I feel that this was necessary due to the nature of the research and also in keeping with the qualitative research design. Initially this advice came from a contact that I made at an INVOLVE (the National Advisory Group for Patient and Public Involvement) conference. During the early stages of my research I discussed my ideas with this individual and they also commented on drafts of the research protocol. It was then decided that it would be useful to have a lay advisor involved throughout the research project. Consequently, a lay advisor was introduced to me through one of my supervisors and they have played a role throughout the research process. Specifically, the lay advisor was not directly involved as a member of any of the case study groups included in this research. During the research I have met with the lay advisor on a number of occasions and maintained contact in between via email and telephone conversations. Certainly, my lay advisor has contributed towards the initial research design, the questions that I have asked and my reflections on the findings. As part of the research process I have sent them summaries of work completed and initial themes and ideas, which we have then discussed. Following discussions I have considered my lay advisor's comments, alongside the comments that I have received from my supervisors and therefore their interaction has been part of the continual reflective, iterative process of the research. This work provided an interesting angle to the overall aim of the research in that whilst the research was exploring public and professional relationships in health research, I also engaged with the ethos of public involvement in research. I believe that this process was an important part of reflexive working and has added a new perspective to the research.

I tried to maintain a consistent diary of my interaction with the lay advisor throughout the project, keeping copies of emails and making note of meetings and telephone conversations that we have had, the outputs from

these meetings and the impact that they may have had on my overall perspective.

3.10. Ethical considerations

As with all research, ethical considerations have played a part in the process that I have followed. These have been both formal requirements and informal reflections. As Stake (1998; 103) suggests, "*Qualitative researchers are guests in the private spaces of the world*". As such, it is important that researchers are respectful of their 'guest' status and ensure that no harm or adverse effects occur as a result of a researcher's presence.

Formal requirements

Ethical approval for the project was granted by the Leeds (West) Research Ethics Committee. In agreement with the requirements of the ethics committee, I made initial contact with potential participants by email and informed consent was acquired from all participants before I commenced data collection.

Each participant received a 'Participant Information Sheet' (Appendix C) and was asked to sign a consent form (Appendix D), consenting to their agreement in the study, their right to anonymity and their right to withdraw their data from the project at any time. I stored all the consent forms in a central project site file which was kept in a lockable drawer in my office. Furthermore, all personal details relating to the study participants, such as full names and contact details, were kept in this lockable cabinet.

Ethical reflections

On commencing the data collection and during the course of the research I have encountered a number of ethical considerations:

Firstly, there were concerns about the potential for conflict of interest. This was a particular concern with regards to the LRP. As I became more deeply integrated into the culture of the panel, I built relationships with the members. I sometimes felt that there may be the potential to blur boundaries as my research aims took a secondary role to work that I may

have to undertake for the group. For example, at times I was taking minutes of meetings for the local research panel, whilst simultaneously keeping my own notes for my research diary.

Secondly, I had concerns about the potential for my disrupting the work of the groups. My main priority, alongside collecting data, was to ensure that I did not prevent any of my case studies from undertaking their normal tasks and objectives. For the CSGs, I made sure that I was as discrete as possible during my observation sessions. With regards to note taking, each situation was judged independently about the appropriateness and timing of taking detailed notes.

A further concern was that despite reading a participant information sheet and signing consent forms, on a number of occasions members of the case studies appeared to forget why I was there. On one occasion a member of the subgroup thought that I was a medical student. Even though I reminded them of my role and research it sometimes concerned me that a minority of individuals had forgotten why I was there and may say things that they wouldn't if they were constantly conscious of my role. This is a key dilemma of much observational research, as some of the most natural interaction occurs once the group are used to the researcher's presence and forget the researcher's identity.

Furthermore, I often felt that I should help the groups out in exchange for them tolerating me observing them. Whilst carrying out field work with the CSGs I would help out by assisting the organiser put out the place names and meeting notes round the meeting table, and then collect them in at the end of each meeting. With the local research panel, although I was employed for a day a week to help with administration, I often put in more hours and helped out with tasks outside of typical administration duties.

Finally, I encountered difficulties actually withdrawing from the research groups. This issue is related to my work with the local research panel. As I became integrated into the core of the group, ending my working relationship was difficult. I managed this process by being upfront with them at all times. After the data collection had drawn to a close I became increasingly aware that I would need to cease working with the group due to personal time constraints. Therefore, I let the group know my plans in

advance and worked with them to find a suitable replacement. Furthermore, rather than completely end my relationship with the group I have continued to attend some of their meetings and provided updates on my research progress.

3.11. Methodological challenges and reflections

As with any choice of methodology there have been some challenges posed by my choice of research strategy.

Firstly the research has been extremely labour intensive. Observation, interviews, continual reflexive practice and diary keeping is an extremely labour intensive process. The demand to continually immerse myself in the research setting sometimes created a situation whereby it was difficult to separate working time from my personal life, or time off. Transcribing the interview data was one of the most labour intensive tasks. At an average speed of three hours transcription for each hour of tape the process was incredibly laborious. However, the benefits of transcribing my own data far outweighed the negatives as I was able to critically engage with the data during the transcription process and reflect on emerging themes and nuances.

Secondly, as all of the Clinical Studies Groups were held in London the travel costs for observation and interviews were high. However, these costs were reduced by use of telephone interviews for some of the data collection.

Thirdly, gaining access to the field presented an initial problem. Recruiting research participants and gaining access to the field can be extremely difficult in qualitative research studies. As already mentioned, during the initial stage one particular strata of the research population (Mental Health Research Network) proved to be extremely difficult to recruit. This meant that proactive decisions often had to be made and consequently the NCRN was chosen as the focus for the main research stage due to my contacts within this group and their apparent willingness to take part.

3.12. Reflexivity

The role of the researcher in qualitative research cannot be overlooked. Unlike some other methodologies, where a degree of distance can be maintained between the researcher and the field of research, most qualitative researchers recognise their impact on the data that is generated. The researcher is the research instrument and as such they are embodied within the research. The account that is presented in this research is one that I have chosen and is influenced by my assumptions, background and motivations for undertaking the research (Taylor, 2002). In order to approach my research in a reflexive manner I have maintained a research journal throughout the process in which I have recorded situations, events and instances that may impact on the research. I have outlined my background and motivations for conducting the research in the introductory chapter of this thesis. As part of the current chapter, I have provided details on my views concerning the nature of the social world and what I perceive to count as 'reality' and accordingly what phenomena I believe to be measurable. Furthermore, throughout the thesis I have attempted to provide my voice, often by use of a personal reflections section or through the use of the first person. In the concluding chapter of the thesis I return to my reflexive account providing my personal thoughts and reflections on the process, the findings and my overall conclusions.

3.13. Summary of the chapter

In this chapter I have provided the methodological framework within which the research can be situated. I have outlined how the data that is required to explore my research questions were best suited to particular theoretical orientations and the implications that this had on the methods that I have chosen. I have given a detailed review of the theoretical and practical implications of my chosen research methods and the sampling strategy that was used.

Furthermore, in this chapter I have also attempted to address some of the concerns that are often associated with qualitative research and how I have worked to deal with these. I have also discussed some of the important ethical considerations that I encountered during the research process.

The next chapter will turn to the empirical data. Providing an introduction to the case studies that were included in this research, the chapter aims to provide the context and background for the cases, along with a more detailed account about the context in which the data were collected and my personal reflections on working with each case.

Chapter Four

Introduction to the Case Studies

4.1. Introduction

As introduced during the previous chapter, the data for the study were collected from a number of case studies using qualitative methods. The selected case studies are part of the NCRN (described in section 4.4.1) and each case reflects one example of a research decision-making setting comprising public and professional membership. In order to contextualise the research findings, the following, relatively brief, chapter will provide a description of each case study. The chapter will begin by providing a justification for the case study selection, followed by an overview of the wider context of the case studies and how they relate to each other. The chapter will then take the national and local case studies in turn and provide a description of the following areas:

- A narrative considering the nature and purpose of each case study.
- An outline of the context in which the observational data were collected and the scope of the data collected.
- My own reflections on each of the case studies.

As consumer is the term that is used within the NCRN to describe patients, carers or other public involved in the research, this is the term that will be used for this chapter and the subsequent three findings chapters (chapters five, six and seven). In order to protect participants anonymity pseudonyms are used throughout this chapter and the remaining chapters.

4.2. Justification of case study selection

The selected cases are all part of the NCRN. As outlined in the methodology, the decision to focus on one condition rather than the three (Mental Health, Dementia and Neurodegenerative Diseases and Cancer) within which I had conducted initial interviews, was based on theoretical and pragmatic reasons. Firstly, there is a clear theoretical case for choosing the NCRN as the main

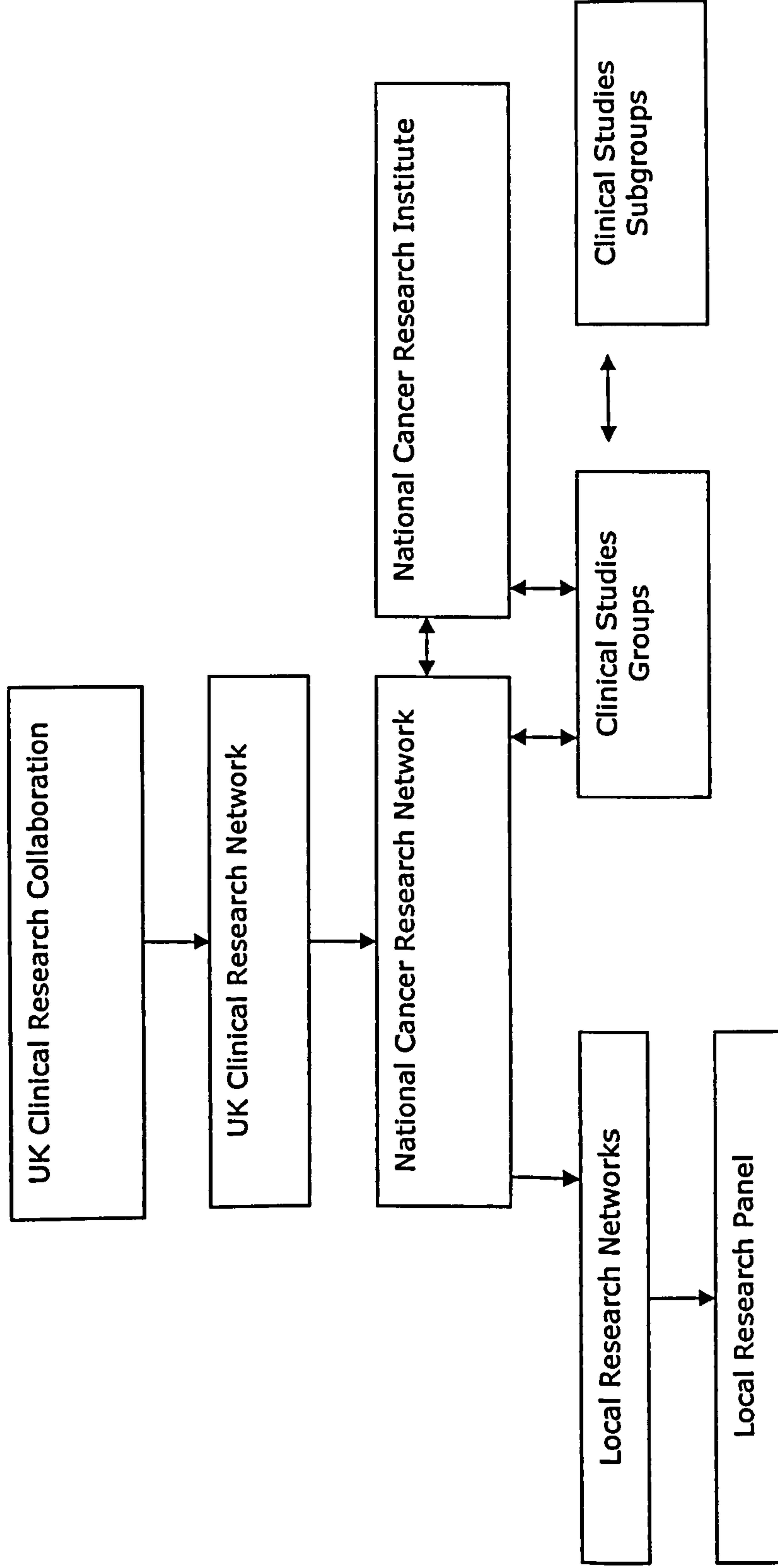
site for the case studies. Primarily, the development of public involvement processes within some of the other networks are in their infancy. In contrast, the NCRN offers clearly established examples of consumer involvement in health research at a national/strategic level and a local level. Therefore, in choosing the NCRN I was able to explore the potential for differences between local and national levels in the practice of consumer involvement in research decision-making. From a practical perspective, the PPI lead for the NCRN proved to be particularly helpful to me and appeared to be interested in the research and its outcomes. This person essentially became a key gatekeeper for me, providing a link between myself and other key contacts in the area. Furthermore, a well established cancer consumer research panel was in operation in my local area, meaning that data collection was fairly practical. The next section will illustrate this in more detail.

4.3. Contextualising the case studies within the national picture

As already outlined, the case studies selected all form part of the NCRN, which links into the UK Clinical Research Collaboration (UKCRC), an organisation that provides the infrastructure for clinical research within the NHS. Figure 4.1 illustrates the organisational structure that the case studies were part of. The three cases selected for this research were chosen to cover local and national levels of public involvement, professional versus consumer weighted groups and both formal and informal meetings. The three levels of case study were:

- **Clinical Studies Groups (CSGs).** These are national groups. They have a relatively large membership (20-30 per group) and are formal in nature. They are accountable to the top levels of the NCRN.
- **A Clinical Studies Subgroup (CSG subgroup).** These are national groups. They have a smaller membership (approximately 10 per group) and are generally less formal than the main CSGs. Their work is fed back into the CSG via the subgroup Chair.
- **A local research panel (LRP).** This is part of one local research network. The group is informal and has a membership of approximately 30 consumers. The local research networks feed into the NCRN.

Figure 4.1: Organisational structure of the case study groups



Consumer members play a role on each of these groups. However, it was anticipated that the nature of the group and the role that the consumer members play within these groups would potentially differ. In exploring public involvement within the NCRN, at both national and local levels and reflecting different levels of formality, it was anticipated that a more holistic account of the extent and nature of public involvement within the NCRN would be provided.

4.4. Clinical Studies Groups and Subgroup, National Cancer Research Institute: Introduction and background to the case studies

The National Cancer Research Institute (NCRI) was established in 2001. It is a collaborative body comprised of, and funded by, partner organisations from the government, charities and industry (NCRI, 2008). The primary objective of the NCRI is to prevent replication of cancer research and to ensure clear communication between partner organisations in order that quality research is effectively undertaken and disseminated (NCRI, 2008). As part of this, the NCRI established CSGs in 2001. The CSGs are managed by the National Cancer Research Network, which is part of the UK Clinical Research Collaboration. Collectively the overall aim of the NCRN and the NCRI is to increase the number of patients entered into clinical trials (NCRN, 2009).

There are currently 22 CSGs reflecting both tumour-specific cancers and more generic research interests (i.e. radiotherapy, complementary therapy). The CSGs are organised by a member of the secretariat, Helen, and her team. I was initially introduced to Helen through the NCRN PPI lead and following this, Helen became a fundamental contact and gatekeeper for accessing the CSG main groups and subgroups.

Officially, the Clinical Studies Groups are the primary route for discussing and developing new clinical trials in cancer research and overseeing existing clinical trials on the NCRI portfolio, i.e. monitoring accrual rates, start and end dates and outcomes (NCRN, 2009). According to the NCRN website, the remit of the CSGs includes:

"...overseeing existing studies, considering new research questions, developing proposals and securing funding from NCRI members and other sources as well as providing expert advice".
(NCRN, 2009)

The work undertaken within the CSGs is directly accountable to the NCRN and NCRI.

NHS, University and industry groups that are developing clinical trials may voluntarily send their protocol to a relevant CSG for approval. If the CSG deems the research proposal to be valuable they may choose to adopt the study into their portfolio of work. CSG approval, or 'badging', is advantageous for research teams for a number of reasons:

- It is viewed favourably by funding, research governance and ethical approval bodies.
- It gives a research team access to some of the most eminent researchers, clinicians and scientists in their area.
- It can help with disseminating research, with sharing and learning and preventing overlap or repetition of research projects.

Membership and Chairmanship of the Clinical Studies Groups is made by appointment through public advertisement and interview, with appointments made by a panel from the NCRI and current CSG Chairs. Whilst each CSG has a variable number of members, common to all groups is a membership that consists of high profile researchers, scientists, clinicians and consumer members. Consumer membership on each CSG has increased from 1 member, during the early stages of CSG establishment, up to 2 members and presently the current NCRN good practice guidelines recommend that 3 consumer members are recruited onto each CSG. No payment is given to any member (professional or consumer) for participation in a CSG, but full expenses (including overnight accommodation if required) are covered by the NCRI. Membership of CSGs by professionals is considered to be a prestigious appointment and also valuable for networking purposes.

The process of appointment of consumer members is different to that of professional members. For consumer members this is organised through the NCRN and is the responsibility of the PPI lead. However, as with professional members, consumer members are formally appointed through public advertisement and interview. This is a recent development and represents an attempt by the NCRN to adopt a more systematic approach to recruiting consumers, rather than the ad hoc, word of mouth system that was followed

previously. In line with the formalisation of the recruitment process, a person specification and role remit has recently been developed by the NCRN.

The CSGs meet twice a year. The duration of the meetings varies between half a day or a full day depending on the size of the group and their trials portfolio. The meetings are always held in London. Prior to the meetings all group members receive the full meeting papers including the agenda and additional documents. The CSG meetings follow a tightly structured format, with each group covering similar core components including: (a) a discussion of potential new projects, (b) updates on the current trials on the portfolio (e.g. start and end dates, accrual rates, dissemination of results) and (c) a consumer feedback section. Variations between the meetings include invited speakers, or presentations from members of the group. Communication between group members may continue in between meetings via email, with discussions about new projects and requests made to consumer members to comment on documents such as patient information sheets.

In theory consumer members are allocated a mentor from their specific CSG who should be their main contact for research based queries arising from the work of the CSG. However, whilst I was collecting data, some of the consumer members told me about how the allocation of a mentor is a somewhat ad hoc process and not all consumer members claimed to have a mentor.

4.4.1. Access to the meetings

My initial access to the CSGs resulted from a meeting with Liz, the PPI lead for the NCRN. Having shown an interest in the research and a stating a willingness to help, I enlisted her help in establishing a link between the CSGs and myself. Through Liz I was introduced to Helen who became an essential gatekeeper, taking the lead in contacting the CSGs on my behalf, passing on my study information sheet, collating responses and arranging my visits to collect observational data. Without the support from these gatekeepers it is unlikely that I would have gained access to observe the CSGs, and my recruitment rate for the interviews would have been significantly lower.

4.4.2. Extent of data collection and context

One full meeting was observed for each of five CSGs on different days between May and September 2008. Table 4.1 provides details about each of the CSG case studies and the data that was collected from each.

At each meeting Helen set a place for me around the meeting table, labelled with a place name. I was given full meeting notes, additional papers and an agenda. During coffee, prior to the commencement of each meeting, Helen introduced me to the Chair, at the same time reminding them of why I was there. She also introduced me to the consumer members, or pointed them out to me so that I could introduce myself. I was a non-participant observer during these meetings, only interacting with people during coffee and lunch times. It was during these periods that I met most of the consumer members and arranged to interview them at a later date.

As part of the initial exploratory work, interviews were also conducted with two consumer members and one professional member of other CSGs. In addition, interviews were conducted with Helen, from the CSG secretariat and Liz, the PPI lead. Data from these interviews have been included as part of the findings.

The documents that were collected and included in the case analysis comprised:

- The minutes of the previous meeting for each group.
- The agenda and accompanying documentation for each group meeting that I attended.
- The official NCRN documentation outlining the role and remit of the CSGs and the role of the consumer members.
- The person specification that was followed for the recruitment of consumer members onto the CSGs

Table 4.1: Case study details

Case study no.	Tumour specific or generic group?	Approximate membership	Number of consumer members	Interviews conducted	Meeting duration
1	Tumour specific	30 members	2	2 professional members and 1 consumer member	10.30 – 16.00
2	Generic	20 members	2	1 consumer member	10 – 14.00
3	Tumour specific	15 members	3	Chair, 1 professional member, and 2 consumer members	12 – 16.30
4	Tumour specific	25 members	3	2 professional members and 2 consumer members	13 – 16.30
5	Tumour specific	20 members	1	Chair and 1 professional member	10.30 – 14.30

4.4.3. Personal reflections

Each session of observation with the five CSGs was very different, although a common format was followed by each of them, in terms of a standardised agenda. As a newcomer I often found entering the meeting room to be a daunting task and felt relieved to have a 'friendly face' in Helen, from the CSG secretariat. It felt feasible to take field notes fairly inconspicuously as the meetings were usually quite large.

I felt that there were some significant differences in the status or credibility that different consumer members had within the various groups and in the way in which the group interacted as a whole. For example, within CSG3, the consumer members appeared to play a vocal role within the meetings, contributing throughout the discussion and interacting with the wider group members during lunch times and coffee breaks. In contrast to this, the consumer members of CSG1 appeared to have a fairly limited input into the meeting, in terms of their

spoken contribution, and there was less interaction between the consumer members and the wider group. These findings are explored in chapter six.

With the exception of one member, it was notable that the consumer members were always extremely happy to help me with, and interested in, my research. During coffee and lunch breaks consumer members frequently approached me to discuss my research. In contrast, I was rarely approached by the professional members and therefore I often felt that they had little interest in the reasons for my observation. Furthermore, on one occasion I observed a couple of the professional members 'snigger' when I explained the scope and context of my research.

4.5. Clinical Studies Group Subgroup: Introduction and background to the case

Each CSG has a number of subgroups, or working groups. These groups focus on developing research in one particular area covered by the main group. The work resulting from the subgroup is reported back to the main group, via the subgroup Chair. One subgroup was chosen as a case for this research. As previously outlined in the methodology, the rationale informing this choice was largely pragmatic, based on time, travel and resource implications. The particular CSG subgroup that was included in the research was selected due to a previous meeting with the Chair when they expressed an interest in involving their group as a case study.

The subgroups are much smaller in size than the main groups. The one included in this research comprised 10 core members, of which two were consumer members. The case study subgroup was relatively recently established (December 2006) and is affiliated to a main CSG that represents a rarer group of cancer disease types. As such, it appeared that the group had worked hard to be recognised and to build up a portfolio of research studies. This seemed to contribute towards a shared goal and sense of pride amongst the group. Both consumer members and the Chair of the subgroup were also active members of the main CSG.

The subgroups meet an average of three times a year. The meeting place varies. The meetings that I observed were held in two large cities in the North of England. The subgroup meetings tend to be much less formal than the main

group meetings. An agenda is set and guides the meeting, but the emphasis is on developing group discussion and debate.

4.5.1. Access to the meetings

I met the Chair of the selected subgroup after she agreed to be interviewed for the initial exploratory work. On explaining the full scope of the research she offered to approach her subgroup about the possibility of them volunteering as a case study. Once she had circulated my information sheets to the group and received a positive response I was invited to observe the meetings. From that point onwards, the Chair added me onto the group's email circulation list so that I could keep up-to-date with the group activities and online discussion.

4.5.2. Extent of data collection and context

- Two full day meetings were observed. These took place between February and November 2008 in two large cities in the North of England.
- One informal coffee meeting with the Chair and one consumer member in September 2008.
- Interviews were completed with the Chair, one professional member and the two consumer members.

The documents that were collected include: meeting notes, agendas from each of the meetings attended, and minutes from meetings attended and the meeting previous to the first one that I attended.

4.5.3. Personal reflections

My experience of the CSG subgroup meetings was different to that of the main group meetings. The meetings appeared to be less formal, possibly owing to the smaller membership, the meeting location and the Chair's approach. There was a general sense that all members, including the consumer members, were at ease in each others' company. This was especially apparent in the periods before and after the meeting when members would engage in general conversation with each other. This was felt to be in contrast to most of the five CSGs that I observed.

The Chair of the subgroup meeting was integral to my research access. I believe her support and enthusiasm for my research was the reason that I was able to

observe the CSG subgroup meetings. However, on the whole I felt that most members, except the consumer members, were relatively Indifferent to my being in the meeting, neither treating me in a hostile manner, nor showing any interest in the purpose of my research.

I felt that I gained a greater understanding of the workings of the subgroup than I did of the main CSGs. This was perhaps due in part to my meeting with the whole group on two occasions. I also had lunch with the entire group at both meetings; I met with the Chair and a consumer member informally for coffee on one occasion; and frequently met up with the consumer members at events of mutual interest, such as conferences and symposiums. The Chair also added me onto the group email circulation list so I was privy to their email contact in between meetings.

4.6. Local research panel: Introduction and background to the case

The LRP consists of a group of approximately 30 cancer patients and carers from a large city in the North of England. The panel was initially established in 2001 by researchers from a university and the NCRN in collaboration with the cancer patients and carers. The group receives funding from the regional cancer network, which covers the cost of administrative assistance (a facilitator for one day a week), members' travel expenses, refreshments and a nominal fee for members' attendance at the quarterly meetings, training events and taking part in other research activities. A researcher from the same university has also established strong links with the group and provides academic support and facilitation on a voluntary basis. The head of the academic department also plays a highly visible role within the group, often attending the group meetings and promoting the work of the panel at conferences and in academic articles, although the need for this role appears to be declining as the group has become increasingly established, showing an eagerness to operate autonomously (this point was frequently vocalised by the Chair). One panel member serves as the panel Chair and another as vice Chair. These posts are appointed through an election process whereby any panel member can nominate themselves.

The group provides a resource to researchers within the university and the local NCRN. Activities that the panel are involved in span the whole research spectrum and include: providing feedback about tentative research ideas, reviewing research protocols, assisting with the development of patient information sheets

and data collection tools, serving as clinical trials steering group members, sitting on research committees, analysing qualitative data, and reflecting on, and disseminating, research findings.

Similar types of local research panel, with a focus on cancer, are in operation across the country. The development of these groups appears to reflect the importance that is given to strengthening local involvement by the major funding bodies in cancer research and the established cancer charities (for example Macmillan Cancer Support).

Requests by researchers for patient and public involvement in local research projects are usually made to the panel facilitator or the Chair. These are then circulated to the entire panel via an email circulation list, and by post/telephone for the 3 members without email access. Panel members respond to the facilitator if they wish to be involved in a particular project and this is then fed back to the researcher to take further.

The panel have four business meetings a year. These have a number of functions. Firstly, they appear to serve a 'checking in' function, whereby members update each other on their recent activities. Secondly, members can collect time and travel claim forms for any work completed. Thirdly, updates are provided on any upcoming projects that may require patient and public involvement, with researchers often attending to give presentations on their work and asking for the panel's involvement. The meetings last about four hours and are held at the same location each time, which was chosen by the panel members and provided by the host university. In between meetings, communication between group members is maintained by the facilitator and through the use of the email circulation list. In addition to the business meetings, the panel meet once or twice a year for training sessions (in research methods and peer reviewing skills).

4.6.1. Access to the meetings

My initial access to a panel meeting was arranged via the (then) secretary of the panel. In early 2007, I emailed the secretary, explained the area of my research and my interest in the panel. I requested their permission to attend a panel meeting as an observer in order to further understand the function of the group and potentially invite them to be a case study as part of my research. I was invited to attend a panel meeting in September 2007. After the initial meeting the

panel members were keen to maintain contact and be included as a case study once my data collection period commenced. Between the initial meeting and the anticipated data collection stage, there was a period of six months during which I maintained contact with the panel. Within this time, the secretary of the panel announced her retirement and I was approached by the Chair to see if I would be interested in taking on some administrative and facilitation activities for the group. After careful consideration of the ethical issues involved with working closely with a group that I would also be researching (see chapter three, section 3.10), and discussing my concerns and the potential benefits and implications with the group, I decided that working with the panel would provide me with a privileged opportunity as a participant observer. As a participant observer, I saw the advantage of potentially being able to gain an in-depth working knowledge of the panel that non-participant observation and interviews might not afford.

4.6.2. Extent of data collection and context

Between March 2008 and the time of writing this thesis I have been assisting the panel for one day a week with administrative and facilitation tasks. Data for this case study were collected between March 2008 and March 2009 and include:

- Weekly email and telephone contact with panel members, the Chair and the facilitator
- At least a dozen informal meetings with the Chair, the academic facilitator and the clinical lead
- 4 full day business meetings
- 2 half day meetings
- 2 training days

Interviews were also conducted with four panel members, the panel secretary and two researchers who had worked with panel members on research projects.

The documents included; Seven LRP annual reports, minutes from meetings held over the data collection year, the consumer member person specification, the role description and material from the LRP website.

4.6.3. Personal reflections on the local research panel

Working with, and researching, the local research panel was a fascinating experience. The group were extremely eager to work with me and there appeared to be a strong sense of pride in what the panel had achieved. This was inferred from the emphasis that was given to producing annual reports for the panel, "*a fantastic document of achievement*" (Robert, carer).

The data collection process, with the local research panel, was a very different experience to that of the main CSGs and the subgroup, which was undoubtedly due to my role as a participant. This often encroached upon my ability to take continuous notes, meaning that more detailed notes had to be written up immediately after the event rather than during. Maintaining a reflective diary became increasingly important as I became more involved with the group, causing me to reflect upon my research aims and the aims of the group. Indeed, at times my role as a facilitator for the group became more dominant than my own research aims, for example at times I would forget to take notes of specific events as I treated my role with the panel as a job. At other times I would prioritise work that needed completing for the panel above undertaking my own research work. Again this emphasises the importance of maintaining a reflexive diary.

As I had been open with the group about my research aims and objectives I felt assured in recording events and conversations in writing. However, as I grew closer to the group I sometimes experienced a slight sense of disloyalty when I observed particular situations that may not necessarily reflect positively on their work. For example, tensions between some group members were observed, these are explored in chapter seven. This is one of the inherent difficulties with ethnographic methods and is both a potential strength and weakness of the research.

4.7. Summary of chapter

This brief chapter has provided an introduction to each of the case studies that are explored in the research. My choice of case studies and decision to base the primary research within the National Cancer Research network is based on clear theoretical and practical arguments, including the established nature of public involvement in the NCRN, as compared with some of the other networks and the

cooperation of key gatekeepers with the NCRN. Furthermore, the range and scope of data that have been collected from each case study has been outlined. Table 4.2 provides a summary of this.

The next chapter of the thesis will begin to present the empirical findings from the research. The findings are presented as three findings chapters. The first, chapter five, will present findings concerning consumer and professional motivations for involvement. Chapter six will explore the integration of consumer members into each of the case studies, therefore the practice of consumer involvement in research. Whilst chapter seven will explore the findings concerned with consumer and professional constructions of credibility in research decision-making settings.

Table 4.2: Summary of data collected

Case Study	Interviews	Observations	Documents
CSGs	14 (6 consumer, 8 professional)	1 meeting observed for each of the five CSG case study groups	<ol style="list-style-type: none"> 1. For each of the five CSGs: <ul style="list-style-type: none"> • Minutes of the previous meeting • An agenda for the meeting and accompanying documentation. 2. Official documentation regarding the role and remit of the CSGs. 3. Person specification and role of consumer members.
CSG subgroup	4 (2 professional, 2 consumer)	2 full meetings and 1 informal coffee meeting	<ol style="list-style-type: none"> 1. Minutes of previous meeting to the one that I first attended, plus minutes of the meetings that I attended. 2. An agenda and accompanying documentation for the meetings that I attended.
LRP	7 (3 professional, 4 consumer)	Observation over a year-long period. Including: 4 full day meetings, 2 half day meetings, 2 training days, over a dozen informal meetings, weekly email and telephone contact.	<ol style="list-style-type: none"> 1. 7 LRP Annual Reports 2. Minutes from meetings for the year. 3. Consumer member person specification and role description. 4. LRP website

Part Two

Presentation of the Findings

Introduction

In the next three chapters (five, six & seven) the empirical findings from the research are presented.

The findings are presented as three discrete chapters, however it is important to note that these findings are interrelated and as such will be brought together in a broader discussion of the main findings in relation to the literature that is presented in chapter eight.

The findings explored in chapters five, six and seven are drawn from interview, observational and documentary data. Table 4.2 in chapter four provides a synopsis of the data collected. In table 5.1 a summary of the interview participants is provided. The chapters will cover the following areas:

Chapter Five: In this chapter, the findings concerned with consumer and professional motivations for initial and continued involvement are considered. It is intended that this chapter will provide an exploration of the differences between consumer and professional motivations for involvement. This chapter draws on the interview and observational data.

Chapter Six: In this chapter the practice of public involvement in the case studies is explored. Specifically how (or if) the voices of the public are integrated into research systems. This chapter primarily draws on the observational data.

Chapter Seven: Building on chapter six, chapter seven is the last of the main empirical data chapters and will explore public and professional constructions of the public claim to credibility in health research. This chapter draws primarily on the interview data.

Table 5.1 Details of interview participants

Pseudonym	CSG/subgroup/LRP	Role
Joanne	CSG	Professional
James	CSG	Professional
Matthew	CSG	Professional
Nicholas	CSG subgroup	Professional
Shona	CSG	Professional
Liz	CSG	Professional (PPI lead)
Helen	CSG	Professional (Secretariat)
Charlotte	CSG	Professional
Louise	LRP	Professional
Karen	CSG	Professional
Peter	CSG	Professional (Chair)
Steven	CSG	Professional
Lisa	CSG subgroup	Professional (Chair)
Jean	LRP	Professional
Victoria	LRP	Professional
Sheila	LRP	Consumer member (Patient)
Fiona	LRP & CSG	Consumer member (Patient)
Mary	CSG	Consumer member (Patient)
Clare	CSG subgroup	Consumer member (Patient)
William	CSG	Consumer member (Patient)
Sandra	CSG	Consumer member (Patient)
Hannah	CSG	Consumer member (Patient)
Anne	CSG	Consumer member (Patient)
Shirley	CSG subgroup	Consumer member (Carer)
Robert	LRP	Consumer member (Carer)
Jenny	LRP	Consumer member (Carer)
Alan	LRP	Consumer member (Patient)

All of the interview participants were of white ethnic origin. Within the professional group the level of professional seniority ranged from relatively junior professionals through to more established professional members. Within the consumer group, whilst participants were not asked to provide their age, it was apparent that the majority were between 50 and 65 years of

age. Furthermore, of the consumer members interviewed it was apparent that most were from professional backgrounds.

Chapter 5

Consumer and professional motivations for public involvement in health research

5.1. Introduction

The previous chapter introduced the case studies, located within the National Cancer Research Network, on which the main research is based. The chapter outlined the context and extent of the data collected and my personal reflections about each case. In this chapter, and the subsequent two chapters, the empirical findings from the research conducted within the NCRN will be explored.

As already mentioned, whilst the findings are presented as three chapters, each addressing a distinct area of analysis and set of themes, it is important to note that these chapters are essentially fluid and interlinked and at times may touch on similar issues. It is intended that the discussion chapter will illustrate this by bringing the key themes together in order to explore the research questions more fully in the light of the research findings and the existing literature.

The literature review outlined the policy claims for public involvement in research, along with the key theoretical perspectives. As part of this it was apparent that five primary arguments for public involvement in health research can be distinguished:

1. A quality claim based on the practical contribution that the public are argued to make to the health research process.
2. An epistemic claim based on the 'different perspective' that the public are argued to bring to the health research process.
3. A democratic claim based on opening research decision-making spaces, which is closely linked to point 4.
4. An accountability claim based on public involvement in research ensuring transparency, and contributing towards renewed public trust, in expert decision-making mechanisms.

5. An empowerment claim based on the belief that involving the public in research is empowering for the public.

In the light of these arguments, this chapter sets out to explore what motivates the public to become involved in research and what motivates professionals to involve the public in research. In particular, how public and professional participants' motivations for involvement compare to each other and the wider policy claims. Accordingly, the data for this chapter is primarily drawn from the interviews conducted with the consumer and professional members of the case study groups.

In order to explore these motivations, Habermas' (1987) concepts of 'system' and 'life-world'¹ will be utilised. As outlined in the literature review, these concepts provide a useful dichotomy between areas of public life that are often associated with lay perspectives, e.g. the life-world, and areas of administrative and political life that are associated with science and medicine, e.g. the system (Britten, 2008; Scambler, 2001).

The chapter will illustrate how many of the consumer members' initial and continual motivations for involvement in research can be located within Habermas' concept of the life-world. These motivations include: involvement in research as an activity to maintain aspects of consumers' lives that had been altered in some way as a result of their ill health; motivations directly concerned with consumers having an impact on healthcare services and research; and consumer motivations concerned with regaining control.

In contrast to this, many of the professional members' motivations for working with consumers in research appeared to be based on systems rationalisations. For example, professional motivations tended to be based on the necessity to involve consumers in research in order to fulfil governance imperatives, along with the specific contributions that consumers may make to improve the outputs of research.

¹ In brief, the 'system' refers to the areas of social life concerned with material reproduction and the achievement of outputs via instrumental rationality. In contrast the 'life-world' refers to areas of social life concerned with cultural reproduction and the achievement of mutual understanding via communicative rationality (Habermas, 1987).

Furthermore, it is suggested that amongst the core cancer consumer group there is an emerging collective identity. This sense of collectivity appears to provide a continued motivation for consumer involvement in research

As already outlined in chapter four, as 'consumer' is the term used within the NCRN to refer to involved cancer patients and carers, this is the term that will be used within this chapter and the two subsequent findings chapters. In order to protect the anonymity of participants, names and identifying data have been removed and pseudonyms have been used. The chapter begins by first turning to the consumer members' initial motivations for involvement in health research.

5.2 Consumer members' motivations for involvement in research

Within the interview accounts constructed with the consumer members, a number of motivations for becoming involved in (and continuing with their involvement in) research were interpreted. Whilst providing a distinction between their *initial* motivations, and their *continued* motivations for involvement can be problematic, I will begin by reflecting on one characteristic that was common to all of their accounts, and provided a primary motivation for their involvement in research – their experiences of cancer.

5.2.1. "...I think I better start at the fact that I had cancer". (Fiona, patient, LRP & CSG)

At the beginning of each interview, consumer members were asked about their motivations for becoming involved in health research. It is perhaps of little surprise that for all of the consumer members interviewed, their initial interest in, and subsequent membership of, the LRP and (or) the CSGs (and subgroup) was primarily attributable to their direct experience of cancer, either as a patient or as a carer.

For example, when asked about how and why he had become involved in research, William (patient, CSG), responded to the question by initially recounting his cancer experience:

"Interviewer: If I could just start off by asking you to tell me a little bit about how and why you became involved in research?"

William: Well first of all I had bowel and the subsequently secondary lung cancer and I got involved by my Haematology and Oncology Day Unit, on their forum. And from that, because of the problems with the local hospital and closure of services, I was a representative on the integration board of [name removed] hospital and [name removed] hospital. And then I went onto sit on the [name removed] Cancer Network Research Group..." (William, patient, CSG).

Similarly, when asked about why she became involved with the LRP, Fiona replied: *"right, urm, I think, I think I better start at the fact that I had cancer"*. Whilst, Clare (patient, CSG subgroup) answered the same question with, *"Okay, well I suppose my journey began six years ago with my diagnosis..."*. These accounts illustrate the centrality of consumer members' diagnosis, a point that would appear to mark a dramatic change in their personal circumstances. Similarly, the three carers within the consumer group began their accounts for involvement by referring back to the diagnosis of the person for whom they were caring. For example, Shirley (carer, CSG subgroup) began, *"Well for starters my husband is a laryngectomy"*.

The data provided above are reflective of the general sense within the wider sample of consumer members in this study, illustrating the direct link between their experiences of ill health and involvement in research. Furthermore, it was apparent that none of the consumer members had been involved in research prior to their experiences of cancer. As indicated above, William's progression into research appeared to occur as a logical progression of his earlier involvement on a patient forum and hospital board. Amongst the other consumer members interviewed, one member (Ben, patient, CSG4) came to be involved in research following an advert for the Chairmanship of a consumer research group. Similarly, two consumer members (Anne, patient, CSG1 and Sandra, patient, CSG2) had applied to the CSGs following adverts in The Guardian newspaper and the 'Big Issue' respectively. In contrast, three consumer members (Alan, patient, CSG3; Fiona, patient, LRP & CSG and Clare, patient, CSG subgroup) were asked to become actively involved in health research via their treating consultant. In a similar way, four consumer members (Hannah, patient, CSG4; Mary, patient, CSG; Ruth, patient, CSG3 and Shirley, carer, CSG subgroup) had been actively approached to be involved in the CSGs through the patient groups

that they were already a part of. Consequently, it was clear that many of the consumer members were already actively involved in a variety of roles within the health sphere. For example, the quotation below from Hannah (patient, CSG4) is illustrative of this:

"...I'm one of the founding members of [name removed] cancer support group...So that was sort of the start of it and from there I got an invitation to see if I would sit on the cancer patients and carers forum...So I was a member of that forum. So then I was asked to join this and that. So I sit on probably half a dozen groups...and then I had a letter from the Patient and Public Involvement lead [name removed] through the forum asking if I would be interested in joining the NCRN".

Finally, the three remaining consumer members (Jenny, carer, LRP; Robert, carer, LRP & CSG and Sheila, patient, LRP) had become involved in research following their attendance at a conference held by a local research panel in their area, having been told about it by a friend or neighbour (Jenny and Robert) and their treating nurse/previous colleague (Sheila):

"How I came to be involved with the LRP was I was actually diagnosed with cancer in 2002 and after my treatment and everything one of my nursing colleagues said to me 'oh there's this meeting at the [removed], you might be interested in going along and taking one of your friends with you'...So I took one of my other friends with me and I was quite impressed with the actual meeting, how it was run and everything else. But it seemed to be concentrated around one specific cancer site and nothing else, which was breast ... And when they asked for feedback, I actually put this on the form...And from my comments on the form and suggestions that I made I was contacted by the panel executive and asked if I would be interested in becoming a member of the panel. So it went from there really".

The above account, provided by Sheila, is illustrative of the way that consumer members' initial disclosure of their diagnosis of cancer, or the diagnosis of a loved one, provided a common focal point at which they began their narrative about their involvement in research. What is apparent from the accounts provided above, and within the wider consumer sample, is that consumer motivations for involvement in research appear to occur as a direct result of their experience of illness, either as a patient or as a carer. Naturally, the research data that is drawn on in this study is taken from accounts of patients and carers who have chosen to become involved in research. Consequently, I cannot account for the reasons why other patients and carers do not become involved in research. However, in the following sections, further aspects of the consumer members' accounts of their

motivations for involvement will be explored. It is intended that these findings will provide a better understanding of what appears to compel some patients and carers to get involved in research. The first set of findings relates to consumer members' motivations to contribute towards improving healthcare services and research processes.

5.2.2. "...I'm all for trying to make things better for everybody".

(Sheila, patient, LRP)

Within consumer members' accounts of involvement in research, it was apparent that aspirations towards improving health research, services and treatment options were paramount. However, unlike some claims that dissatisfaction with services forms a primary motivator for involvement (for example, Contandriopoulos, 2004; Sharp, 1984), commonly held aspirations to improve healthcare provision and research seemed to be held regardless of the consumer member having experienced poor, adequate or exceptional healthcare.

For example, Anne (patient, CSG1), reflected on how her poor experience of treatment and care provided an impetus for her to become involved in research:

"...I was just sitting in the garden one day reading The Guardian and here was an advert for, request for consumer members on the National Cancer Research. And I thought 'gosh that looks interesting, maybe I should just find out about it?' And it was all very tentative really, and I did find out about it and thought it sounded just my cup of tea. So I decided to apply for it. I'd never previously been involved with any sort of support group... I was never part of one, for two reasons really: one was, there wasn't one for my cancer, because I've never actually met another person who had my cancer, so my support has been online support with people in America; and maybe, I didn't want to go to a generic cancer support group, I didn't feel the need for that. So I've never been involved in that way. So I wasn't looking at it at all from the support angle. I was actually looking at it from the point of view that maybe I could use, I don't know, some of my previous experience to help in some way. I think my, and I hate this phrase but everyone seems to use it, my cancer 'journey' has been quite an eye opener to me I suppose. I was totally and utterly gob smacked by the way I was treated. Some ways I thought it was appalling, other ways it was fine. And I suppose what I thought was that if I got involved in something like this maybe I could have some impact in some way" (Anne, patient, CSG1).

Interestingly, whilst Anne professes that she didn't approach involvement in research as a form of support group some parallels can be inferred between her motivation for involvement and the potential outcome from being involved in a support group. For example, in drawing on her poor experiences of treatment and care as a motivation to become involved, it would seem that Anne was able to work towards recasting her poor experience in a more constructive manner.

Similar to Anne's account, William's (patient, CSG) account for involvement highlighted his desire to use his poor experience of treatment and healthcare in a constructive manner by contributing towards changing the existing healthcare service provision:

"Interviewer: *So what was your original motivation then for becoming part of these groups?*

William: *To really to make the pathway better than what I had actually had. I didn't have a particularly good pathway but I didn't want that to be the, you know I didn't want to just moan about that. I've actually written my letter of complaint about the hospital and realised that nobody took a blind bit of notice unless you actually had something serious or died. So it was a case of trying to change things before they actually became as bad as, you know that kind of situation" (William, patient, CSG).*

It would appear that involvement in research provided William with an opportunity to present his complaints in what he feels is a constructive manner. Highlighting that he '*didn't want to just moan about that*', by becoming involved in research it would seem that William perceives he is taking positive action. In this way, it could be argued that as illustrated within Anne's account, whilst not specifically offering a support group function, becoming involved in research after a poor experience of cancer treatment or services may provide some form of cathartic outlet. Accordingly, these accounts (i.e. Anne's and William's) are seemingly located in the realm of the life-world. Their initial motivations for involvement in research appear to be based upon communicating their experiences of ill health and services in order that health professionals and researchers may understand these and subsequently act on them.

In contrast, other consumer members spoke of a positive experience of treatment and/or care as providing an impetus for their involvement in research. For example, Mary (patient, CSG) spoke of her feelings of *gratitude*

for the treatment and care that she received. In this way, Mary accounts for her involvement as a mechanism to 'give something back':

Interviewer: *How do you feel your involvement in research has benefited or disadvantaged you, if at all?*

Mary: *I think it's more to do with how it's benefitted them really. I hope anyway. I mean I'm there for their benefit, not for mine.*

...

Interviewer: *So have you personally gained anything from being involved?*

Mary: *Erm, yeah I like to think that I'm helping. I think I'm still here which is highly unusual for someone who's had [my type of] cancer. And so I erm, you feel grateful that you were well treated and I was on a trial, which okay I might well have survived without the trial, I'll never know. But you just feel as though you want to give something back, you want to help others. I suppose that's it" (Mary, Patient, CSG).*

In claiming to 'want to help others', Mary's account appears to have altruistic qualities. Altruistic accounts for involvement, driven by a good, indifferent or poor experience of treatment and care, as demonstrated in the extracts provided above, were reflected throughout many of the interviews with the consumer members. These accounts arguably challenge simplistic notions of the health care consumer who treats healthcare as a commodity. Instead, the altruistic nature of these accounts may be suggestive of a sense of shared ownership of the healthcare system, with involvement in research representing a form of social capital – a way of re-establishing civic participation and a sense of belonging.

In a similar way to Mary, Ruth (patient, CSG3) also spoke of *giving something back*. In accounting for her motivations for involvement, like Mary (above), Ruth's account appears to be related to her sense of gratitude for her continued survival. In the extract below Ruth is responding to a question about her motivations for becoming involved:

"I think a lot of reasons really. One of them was that, to try and make things better for other patients, that was one of the big reasons. And also to try and give back something because they've treated me and I thought that's one way of giving something back. And also with [my type of cancer] it's such a rare cancer and often people are diagnosed very late, so that was an impetus for me really. There's a lot of research into other cancers but because [type of cancer removed] is

so rare there's not much known about it and the survival rate's not really improved over the last 30 years that was another reason. And also I think, well I've had to give up work and it was another way of giving meaning to life really" (Ruth, patient, CSG).

Several motivations are apparent within Ruth's account. Firstly, in claiming a desire to 'make things better for other patients, it would seem that Ruth is motivated by a degree of altruism. Secondly, it is apparent that in being given the 'gift of life', Ruth also feels compelled to become involved. Involvement could potentially be conceived of as a way for Ruth to 'repay' healthcare services in exchange for her continued survival. Thirdly, Ruth identifies her rare form of cancer and associated lack of knowledge or research in that specific area, perhaps highlighting her desire to promote, or support the research that is done. Finally, Ruth explains how she had given up her work prematurely due to cancer and therefore involvement in research 'gave meaning to life'. This is suggestive of continued involvement in research as a mechanism for replacing elements of consumer members' 'pre-cancer lives'. The next section will turn to this idea in more detail.

5.2.3. "I used to lecture ... before I had my cancer". (Mary, patient, CSG)

In this section I explore aspects of consumer members' accounts that appear to identify involvement in research as providing a mechanism to fulfil aspects of their lives that had changed following a diagnosis of cancer. In particular, in this section I will explore the findings concerned with the relationship between involvement in health research and consumer members' working lives.

Within many of the consumer accounts' for involvement there were references to the premature end of a career. For example, in the previous section, Ruth (patient, CSG) explained that in the context of the end of her career, involvement in research gave meaning to her life. In a similar way, Anne (patient, CSG1) explained how her diagnosis of cancer had dramatically altered her life in a number of ways:

"Okay well I suppose having a career where I was very involved in, I was in education and I was head of a nursery school for a while, and I was an inspector for a while. So I had quite an exciting career where there were lots of things going on and life was very full and my brain was constantly being challenged and everything. And then along came

cancer which, you know stops you short really, and my cancer was a cancer that I wasn't really expected to survive from and touch wood I am still surviving, but it's obviously made me look very differently at life and I was getting older and after having 6 months off while I had the cancer which was recommended to me because I was working with young children and families and they said it was too dangerous in terms of the bugs and things I could pick up, so I had 6 months off and then I started to go back part time and I started to build up my workload. And it just became evident really that it wasn't working. I couldn't work in a position of responsibility really when I couldn't work 100 percent. And I wasn't able to work 100 percent. So the decision was taken that I would finish, which I did. And at first that was fine it was really exciting. It was 'oh I've got all this time, isn't it wonderful?' You know and I went on lots of walks and did all sorts of exciting things. Kept a little bit of work going, but after having the sort of life I had had, I think I just started feeling a bit as if I wanted to do something" (Anne, patient, CSG1).

There are a number of inferences within Anne's account. Firstly, it appears that a diagnosis of cancer meant that Anne's 'exciting' career had ended. In referring to her career as 'exciting' it would seem that this was a part of her life that Anne enjoyed. Furthermore, Anne explains how she made several attempts to return to work after her treatment, highlighting the importance that work played in her life and her need for the 'constant challenge'. Secondly, whilst not initially apparent, following the premature end to her career, Anne felt that she 'wanted to do something'. Consequently, one could argue that involvement in research is one activity that Anne is able to undertake because of, yet despite, her ill health. In this way, involvement in research appears to 'fill up' these 'lost' aspects of her life.

Similarly, Alan (patient, CSG3), spoke of the benefits of involvement in research as giving him 'another set of interests' to replace a lost career:

"It's given me another set of interests. At a time in my career when I was ready to have another set of interests, partly because of being in treatment for nearly 2 years you lose a lot of currency in the market you're working in...And I effectively had to give it up. And so I think it's given me a whole set of interests and opportunities which have been challenging and demanding at times, but are enjoyable" (Alan, patient, CSG3).

Again, Alan's account appears to frame involvement in research as a way to replace lost aspects of his life. As with Anne, Alan readily admits that as a result of undergoing a prolonged period of treatment his 'currency' within his career was diminished. However, rather than dwelling on this, Alan accounts

for involvement as providing him with fresh challenges and new interests, thus reflecting on his experiences in a positive and constructive manner.

The interview extracts provided above are illustrative of a number of the consumer accounts of involvement. They appear to indicate that consumer involvement in research provides some form of proxy for consumer members' previous jobs or career. Building on this, Sheila (patient, LRP) explained how she had a medical background. Although she no longer practiced medicine on account of her ill health, involvement in research appeared to enable Sheila to maintain a professional interest in the area:

"Interviewer: *So what would you say your motivation is then for being part of these groups?*

Sheila: *To improve the services that are available. If you look at the NICE and the government directives and all that, big brother's watching you type things, then obviously there is a lot that needs to be done. It's quite interesting from my point of view because with the medical background that I've got, although obviously through ill health I no-longer practice, I'm still very interested as to what my colleagues have to do to jump through the hoops to get their pay at the end of the day. And it can be, I think very off putting for a lot of people. Much of what has to be done today is a lot of paperwork involved, despite the fact that computers are leading it, it still needs imputing and I think there is a danger, this is my opinion only, that the care has gone out of the scenario and I find that very distressing and totally appalling. Because that's not what I learnt medicine for and practiced medicine. As I say I'm of the old school and therefore old habits die hard. Yes there is room for a lot of improvement and I believe that we should be moving forward but there is a way to do it. And I sometimes feel that a lot of these meetings I do attend as the patient voice capacity, if I put my other hat on as a medical professional I think we're just trying to reinvent the wheel in a different way, square instead of round. And it does seem bizarre to me when it's the end product, patient care that really matters" (Sheila, patient, LRP).*

In the extract above, Sheila identifies her primary motivation as improving healthcare services. Furthermore, it is apparent that in identifying her general interest in the continued professional aspects of her previous career, involvement in research serves to maintain some elements of Sheila's 'professional self'.

Interestingly, whilst another interviewee, Robert (carer, LRP & CSG), never directly referred to the loss of a career as having impacted on his decision to become involved in research, the observational and interview data revealed

that through involvement in research, Robert had effectively carved out a career as a consumer member of research decision-making groups. Indeed, throughout the course of the data collection he became increasingly active in various consumer research related roles, to the point that the majority of each week was spent by him working as a consumer member. This was something that was highlighted by one of the professional members of the LRP (Jean) who felt that Robert *"...came to the panel and was keen to get a job."* During a subsequent interview with Robert I noted that his involvement in research appeared to have become a full time occupation, to which he replied:

"I think the fact that I've got this experience of [cancer type removed] cancer has helped because the minute any [cancer type removed] cancer project anywhere in the country crops up then my name tends to come to the forum and I get contacted as a result of that. And that spreads into other requests that I get. But literally, well I'm all over the country talking about user involvement in cancer research. I did a list of towns that I've visited recently yesterday, about 12 cities all the way from Newcastle in the North to Slough and Bristol in the South of England. So I'm here there and everywhere and the list grows... So, it [involvement in research] has become yeah. But I was in a position where that could happen because of the way my life had panned out. I had time to give to it. Fate I suppose to some extent. But yeah, fate cast me upon this beach and here I am building a sandcastle" (Robert, carer, LRP & CRP).

The extract above is certainly illustrative of Robert's increasing involvement in research. Throughout the year of the data collection it was clear that his commitment to consumer involvement in research was gradually increasing and he was observed attending an increasing number of conferences and strategic level research decision-making committees. Robert was clear in the impact that involvement in research had on his life:

"...I mean it's made a gigantic difference to my life in that it's become my major, apart from my personal life, I think I spend more of my life involved in, it's become a part time job effectively...So it's been gigantic for me" (Robert, carer, LRP & CSG4).

In a similar way, whilst Ben (patient, CSG4) never spoke of involvement in research as a replacement for a lost career, when asked about how he had become involved in research he explained how he had initially approached involvement as a potential job opportunity:

"...well actually I saw an advert for the Chair of the consumer liaison group and before that I wasn't aware of it [consumer involvement in research]."

In this way, for Ben the appeal of involvement in research appears to be the potential for his career development.

However, in contrast to the majority of consumer members' interview accounts that referred to a lost career as providing an impetus for involvement in research, during the observations of the CSGs and the LRP it was apparent that this might not apply to all consumer members. For example, within the LRP some members continued in their existing employment, whilst a couple of the members had never been in full time employment. However, it was not possible to conduct interviews with these members and therefore it is impossible to reflect on this beyond a passing observation. Nonetheless, from the consumer members' interview accounts that are available there appears to be a clear connection between changes to their professional lives and their motivation for becoming involved in research decision-making groups.

Building on this, the next section explores a further way in which involvement in research fulfilled elements of consumer members' lives. Specifically, the next section explores how involvement in research enables some consumers to develop new skills.

5.2.4. "Oh it keeps your head ticking doesn't it?" (Jenny, carer, LRP)

This section explores an additional aspect in which involvement in research appeared to provide a sense of fulfilment for the consumer members. In particular, this section explores the findings concerned with the mental stimulation associated with involvement in research and the potential to develop new skills. The opportunity to develop skills and undertake training was a by-product of becoming involved in research and, as such, appeared to contribute towards consumer members' motivations for continued involvement in research.

It was apparent that some of the consumer members seemingly valued the opportunities that involvement in research gave them to learn and develop new skills. For example, when talking about the benefits of involvement in

research, Alan (patient, CSG3), spoke of the enjoyment and 'intellectual stimulation' that he associated with being involved in a Clinical Studies Group:

"...on a much more surface level it's actually very enjoyable and intellectually stimulating. I felt very challenged by getting to understand research, I gave up science after O' Level at school so I'd studied no science since I was 16. All my daughters have science degrees! But then, don't underrate the stimulation of being involved with some very clever and very able people and learning from them and on occasion contributing and realising that they're valuing what I'm inputting" (Alan, Patient, CSG3).

The extract above is illustrative of the enthusiasm that was evident amongst some of the consumer members towards undertaking training and learning new skills. For example, throughout the data collection period, Robert (carer, LRP & CSG) was observed to be eager to attend a great number of training courses ranging from systematic review, through to statistics and qualitative data analysis. Indeed, in his role within the LRP, Robert was fundamental in organising training days for the wider consumer group during which he keenly passed on the skills that he had acquired during these courses. My observations of his actions during these training days led me to believe that Robert enjoyed playing the role of the educator to the wider group.

Other consumer members also referred to their enjoyment in developing skills through their involvement in research. For example, Fiona (patient, LRP & CSG), spoke of her satisfaction at being able to critically reflect on research findings that are presented in the mass media:

"I think I am starting to get a lot more of an awareness about what the research actually means. And for me, I like learning and it's very interesting to see where the research is coming from and actually understand a bit more about the process [that contributes to] what twaddle comes on the telly and the papers, and the underlying messages from them" (Fiona, patient, LRP & CSG).

Furthermore, Fiona (patient, LRP & CSG) explained that prior to the training that she had undertaken in order to be involved in a research capacity, she had developed key skills that she felt were necessary in order to manage her treatment and care:

"... I think one of the things I learnt was that in order to determine what treatment I had, I had to negotiate with the people who were doing my care. And I had to go very quickly from having no knowledge at all of cancer to be able to critically evaluate what people wanted to do for me" (Fiona, Patient, LRP & CSG).

The language used by Fiona is of particular relevance here. For example, the use of '*critically evaluate*', is illustrative of the type of technical language that was found to be used by many of the consumer members throughout the course of the research and is potentially suggestive of their educational/professional background (as explored in section 5.2.7). Furthermore, it is perhaps illustrative of the way that many consumer members were seen to adopt the terms of the dominant discourse, with the potential for consumer professionalization (as will be explored in chapter seven).

Developing skills to understand and *critically evaluate* techno-scientific literature and research was found to be useful for some consumer members' in negotiating their treatment and care (for example, Fiona). Giddens' (1991) notion of 'lay re-skilling' is a potentially useful concept for reflecting on consumer members' engagement with techno-scientific discourse. As outlined in the literature review, 'lay re-skilling', as defined by Giddens', is a mechanism for lay re-engagement with expert systems in order to make *reasonably informed choices*, in this case related to treatment and care (Giddens, 1991; 141). The extract below, taken from an interview with Jenny (carer, LRP) discussing the benefits of involvement for the general patient population, is illustrative of this point:

"I think the opportunities of doing research are more open now. It was a closed door at one time. They went off and did the research and we benefited or didn't. But now people are more aware that if they want to, they can be involved. They can find out about it and that door's not quite as tightly shut as it used to be, it's not as open as it should be but at least there's a foot there. And I think two worlds now can become a little more open and discuss it. And to be a little bit more aware when you go to the doctor's and you're given a drug, you know where's it come from? Why have I been given this? ... And probably it gives patients a little bit more power to get involved in what's the matter with them, cancer or any other disease. That they're not just there for the convenience of research. They don't get poorly because somebody's going to benefit it, you know and they can be part of the process. At one time you'd be told, you take this and that's it, weren't you? But I think it will alter it will change. It has given people a little more power. But they've to use that power carefully. Not become stroppy or demanding. You know - they think there's a drug and they want it" (Jenny, carer, LRP).

From Jenny's account, it would seem that she associates opportunities to engage with research as potentially, and actually, empowering experiences. Irwin and Michael (2003) suggest that consumption of the available techno-

scientific information provides patients with the opportunity to regain some sense of control (or empowerment) amidst biological circumstances that are very much outside of their control. Certainly, in the case of Alan (Patient, CSG3) this idea appears to hold true, as the quote below highlights his claims that engagement with the techno-scientific discourse was indeed empowering:

"To me I suppose the great empowering thing is that I feel that I am discussing scientific things for the first time in my adult life (laughs). You know as I said I gave up science at the age of 16 and yet okay I'll never be a statistician and I'll never understand the equation they use to arrive at the numbers you need to accrue into a trial for a specific randomised trial etc. But at least I'll understand how it happens and why it's necessary and the impact of getting it wrong and the impact of getting it right. And I can take part in those type of discussions. And that I find empowering in one very personal sense" (Alan, Patient, CSG3).

However, not all of the consumer members approached the opportunities for training with the enthusiasm and zeal that is illustrated in the extracts above. Particularly within the LRP, there appeared to be some resistance to engaging with the techno-scientific discourse and training opportunities. Consequently, the notion of lay re-skilling, and the possibilities for consumer empowerment were not experienced by all consumer members. Moreover, it appeared that for some consumer members, their resistance to training actually resulted in them feeling disempowered. For example, it was apparent that some members of the LRP began to question their own role within the panel in the face of their inability or choice not to take part in training. This issue is considered in greater detail in chapter seven, section 7.2.6 (*'training as a form of system/life-world antagonism'*).

In the next section, I will build on the findings concerned with discourses of empowerment.

5.2.5. Empowerment

The literature review highlighted how empowerment is often cited as a primary rationale for involvement in health policy and the wider theoretical literature (Boote, Telford & Cooper, 2002; Hanley et al, 2004; Lindenmeyer et al, 2007) and certainly, some of the data appears to support this. A couple of the consumer members constructed empowerment as the opportunity to

develop new knowledge and skills (as discussed above). Other consumer members talked about the ability to make changes to services or recast their experiences of treatment and services in a more positive light, with involvement in research providing the opportunity for consumer members to take constructive action rather than destructively dwelling on their illness experiences (as illustrated above in section 5.2.2). Furthermore, in fulfilling aspects of consumers' lives, specifically related to their career, it was suggested that involvement in research gave 'meaning to life'. Arguably, issues around empowerment are central to these ideas.

Building on this theme, within some of the consumer members' accounts, there were suggestions of an emerging discourse concerned with regaining a sense of personal control as a result of active involvement in health research. For example, during one meeting that I observed, the importance of regaining control was made explicit by Lucy (Patient, CSG3). During this meeting Lucy articulated to the Clinical Studies Group her own sense of guilt at not having 'badgered' her clinicians for an initial diagnosis. This can be seen in the extract below taken from my observation notes:

"Lucy is next to speak. She thanks the group for letting her be there. She tells them that she has had a fear of GPs and only recently, two years later after attending the CSG meetings does she now feel that she has gotten over it. She tells the group that her fears were related to the difficulties that she encountered getting a diagnosis but that she also feels partly responsible for not having badgered her clinicians. At this point she looks to be welling up and is becoming quite emotional. She says that this is her second meeting, effectively meaning that she is a third of her way through her tenure as a consumer member...Because of this she urges the group to draw on her saying 'I'm here, I have a perspective. So use me if I can help you!' (Observation notes from CSG3, May 2008)

This extract seems to infer an implicit connection between, Lucy's associated sense of guilt from her failure to appropriately engage with the healthcare system and her resulting active involvement in research. In becoming involved in research, it could be argued that Lucy is taking control and making a personal choice to engage with health professionals and research.

However, it is apparent that empowerment is a complex and multifaceted issue. For example, whilst Ruth (patient, CSG3) talked about the 'empowering' effects that she associated with involvement, she also highlighted the potential difficulties associated with involvement and the

discourse of empowerment. Moreover, Ruth's account illustrates the emotional impact of involvement and reminds us of the centrality of the life-world in relation to accounts of public involvement in research:

"Ruth: It makes me feel that I'm doing something useful. Because you then actually are contributing and trying to make things better so in that sense it's empowering, but I don't like that word. But it's also extremely tiring and it's actually quite emotional because you are thrown together with other people with cancer. So when you meet, you know for coffee and things like that, you're hearing all these stories of people with cancer because it's a natural thing for people to talk about their cancer. So you're hearing all that and it's actually terrifically emotional.

Interviewer: And you said that you don't like the word empowerment. I would be interested to know why that is?

Ruth: It's just jargon. Thrown around and you think what does that actually mean. You hear so many people talking about it and when you're actually a cancer patient what could possibly empower you? I just want to have the right care, you want to be seen by the right people who know what they're doing, and get the right treatment. We've got one of the poorest records of survival with cancer. I just don't like the jargon, I think there's so much jargon banded about and you don't know what's the real reason behind it".

What is apparent in Ruth's account is that involvement in research is ambiguous and seemingly contradictory, encompassing both negative and positive outcomes for consumer members. Whilst Ruth described her sense of empowerment from trying to make things better, e.g. recasting her illness experience in a constructive manner, she also points to the considerable emotional and physical effort that most consumer members go to in order to take part. Furthermore, by exclaiming '*when you're a cancer patient what could possibly empower you?*' Ruth provides a powerful reminder of the sense of passivity that is often experienced by cancer patients and as such provides a critique of the discourse of empowerment. This clearly highlights the potentially complex and contradictory nature of public involvement in research.

The chapter will now turn to findings that reflect on one final way that involvement in research was identified to fulfil aspects of consumer members' lives. Specifically, the next section concerns the development of social bonds and networks.

5.2.6. "It has all sorts of social and personal functions for people on our panel..." (Jean, professional participant, LRP)

Having so far explored the findings relating to involvement as fulfilling aspects of consumers 'professional self', the potential for developing new skills and the associations between consumer involvement in research and empowerment, this section will consider the social aspects of involvement. Specifically, it would seem that public involvement provides a social/supportive function for patients and the public.

For example, particularly within the LRP, it was clear that the group served a supportive function, in addition to its remit for research. When a consumer member became ill, or relapsed, there was an immediate sense of 'rallying round' as other members made sure that the individual was supported both emotionally and physically. For example, when Sheila's (patient, LRP) cancer returned, Fiona (patient LRP & CSG) was an important support for her. During one LRP meeting in October 2008 I noted how Sheila had told me about '*how brilliant Fiona had been, taking her to and from meetings, hospital appointments and keeping her company*'. Fiona had simply replied '*that's what we're here for, we look after each other*'.

During the data collection period it became clear that the LRP secretary, Jean, played a central role in fostering the support group element of the panel. Jean spent a great deal of time contacting members to check on their wellbeing, and was always quick to inform the rest of the group should a member become ill. This contributed towards a supportive function within the LRP that was not evident within the CSGs. In this way, within the LRP the centrality of life-world aims were apparent. During an informal discussion with Jean in March 2008, I noted how she explained to me that she was keen to emphasise the supportive function of the group and was worried that this function may be lost as the LRP became increasingly focussed on research. It seemed that Jean was concerned that the life-world function of the LRP could diminish as research, or indeed systems rationality, took precedence. However, as will be explored in chapter 6, not all of the consumer members of the LRP were happy with the supportive function of the LRP. For example, Robert (carer, LRP) often told me how he was keen that the panel wasn't viewed as '*a talking shop*', clearly attempting to distance the group remit from that of a support group.

In contrast to the LRP, within the CSGs, the social/supportive function did not appear to be as pronounced. This was perhaps due to the more infrequent nature of the meetings and the geographical diversity of consumer members in the CSGs as compared with the LRP. Nevertheless, the observational data did highlight a certain sense of common purpose between the consumer members of the CSGs. In particular, during one central meeting for all of the consumer members of the CSG, I noted the atmosphere within the room:

"Following Robert's (LRP and CSG) introduction to the meeting there are a series of presentations by consumer members. The first one is to be given by Alan (CSG3). Robert introduces Alan's slot by telling the group how pleased he is to see Alan return to involvement in research, following a leave of absence due to ill health. As Alan approaches the front, a round of applause breaks out for him. Alan looks noticeably touched and smiling thanks the group saying how great it is to be back amongst friends" (Notes from a consumer meeting, September 2008).

In most cases where social bonds had developed, these were seen to be between consumer members. However, in a small number of cases it was apparent that some social bonds had developed between consumer members and professionals. For example, Louise (LRP, professional participant) became quite emotional when talking about the close friendships that she had formed with two (former) consumer members of the LRP:

"... I developed two friendships and one very special friendship with somebody who I never otherwise would have met. Although I think that's possibly unusual although I do know other friends who have done research and involved consumers who have developed good friendships with people that they've worked with as well" (Louise, professional participant, LRP).

Accordingly, it became apparent that within the wider consumer group there was an emerging sense of collectivity. Developing social bonds and networks contributed towards a feeling of community within the core consumer group of the NCRN. The next section will turn to other aspects of this emerging sense of 'group collectivity' that were apparent within the consumer group.

5.2.7. Group collectivity

As already mentioned, the development of social bonds and networks contributed towards a sense of group collectivity amongst the consumer

members. As a further aspect of this sense of 'collectivity', it appeared that there were some commonalities amongst the consumer members regarding their social background, values and personal ethics. For example, a number of the consumer members voiced an interest in wider healthcare systems and organisations, above and beyond those purely dealing with research. This included, Clare (patient, CSG subgroup) who was active in voluntary sector organisations:

"I became involved in the [name remove] user group on the voluntary side. I was already involved in various initiatives in my home area, building on my past in the voluntary sector and as a member of a community health council" (Clare, patient, CSG subgroup).

Similarly, Alan (patient, CSG3) and Hannah (patient, CSG4) were founding members of cancer support groups in their local areas. Other consumer members were involved in strategic groups. For example, one of the members of the LRP was a member of the Human Tissue Authority, whilst another member served on a local research ethics review panel.

In this way, consumer involvement in research, within the National Cancer Research Network, at local or national level, can potentially be viewed as a further extension of some consumer members' tendency towards active civic participation. In fact, as discussed by Ben (patient, CSG4) when talking about why involvement in research interested him, it appeared that he regarded it as a *natural extension* of his personal and professional interests:

"...well I think generally I'm obviously interested in, if you like, giving a voice to people who have experiences of service and the NHS. We're talking about here in general, and people who've had cancer in particular. So obviously having had that experience I suppose I feel my contribution is possibly more valid than other people's. And there are also lots of other roles that I've been involved in over the past few years [and they] have largely been about bringing my experiences to them and trying to influence services to make improvements. I just saw this as actually a natural extension of becoming involved and trying to influence" (Ben, patient, CSG4).

Some consumer members had careers that had some connection to health, health research, or service improvement and this appeared to have a strong influence on their interest in cancer research. Sheila (patient, LRP) and Ruth (patient, CSG3) were both health professionals, as a GP and a nurse respectively. Fiona (patient, LRP & CSG) and Ben (patient, CSG4) had careers in social services, which they felt had contributed towards their

Intrinsic desire to improve services, whilst Robert (carer, LRP & CSG) had been a science teacher. Robert's interest in the scientific aspects of cancer research was made clear during an interview when he talked at length about the developments in scientific research:

"I have done some science research. 30 years ago, I mean the biochemistry that I worked on was at a totally different level than it's at now. And I can go and sit and listen to a bioscience lecture at National Cancer Research Institute conference and literally after the first few sentences the science that I knew has disappeared into the background. And I mean some of the talks about the way DNA functions is miles beyond some of the theory that I learnt about at university. I mean they'd only just elucidated the structure of DNA when I went to university, the actual physical shape of the molecule was something new and the way that it replicated. But now, I mean it's obvious if you go to a science lecture that things have moved on massively" (Robert, carer, LRP & CSG).

Other consumer members' professional backgrounds included: teaching, school inspection, law and journalism. In fact, it was apparent that professional backgrounds were the 'norm' amongst the sample consumer group. This certainly appears to reflect the wider literature that suggests public involvement in healthcare is most common amongst those from higher socioeconomic groups (Campbell, 2005; Martin, 2008). Yet, there were some exceptions to this. In particular, within the LRP there appeared to be a slightly more diverse range of socioeconomic backgrounds. For example, Robert (carer, LRP & CSG) explained this:

"...our experience tends to be that they're usually people 40, 50 plus, I better be careful I don't insult anybody, from reasonably well educated backgrounds. But occasionally you get the sort of real gems, people who've not had a strict formal education, but they've joined the group and they honestly give their opinions and very valued opinions and very important opinions because they are from hard to reach groups" (Robert, carer, LRP & CSG).

However, whilst Robert believed that the opinions of such *real gems* were valued, my own experiences of the LRP suggested that consumer members who did not have a professional background were in fact often marginalized. During an informal conversation with one of the professional members of the LRP, I remarked that I felt the group tired of one particular member and that his comments appeared to be frequently dismissed. The professional member replied that the consumer member in question was '*from a working class background*', stating that this may have contributed towards the way that the wider group received him. In this way, it appeared that because the

member in question did not fit with the socio-economic status of the majority, his place in the group was perceived as potentially problematic.

Whilst the findings have illustrated how many of the consumer members were active within wider consumer groups and organisations, perhaps hinting towards an emerging set of shared values, this 'model' certainly did not apply to all. Nevertheless, it appeared that the collective NCRN consumer identity has a strong influence over its members. For example, some consumer members expressed feelings of guilt for not fitting in with this collective identity. For example, two consumer members (Anne, patient CSG1 and Sandra, patient, CSG2) talked about their feelings of guilt regarding (what they considered to be) their limited commitment to involvement in research at a range of levels. During the interviews with Anne and Sandra, there was a strong indication that they both felt a sense of personal responsibility to commit more to involvement in research beyond that of their appointment on a National CSG. The extract below, taken from an interview with Anne, highlights this. Here Anne is talking about why she became involved in additional consumer groups beyond the CSG:

"Well if I'm being brutally brutally honest it was guilt really. I thought 'oh I really think I ought not to be just doing this national thing. I ought to be involved locally'. So it started off as being a guilt feeling really, nobody put the pressure on me it was myself you know" (Anne, consumer member, CSG1).

Whilst Anne states that '*nobody put pressure on her*' to become more widely involved, one might argue that the personal pressure that Anne experienced may be a by-product of the strong core value identity amongst the consumer members. In relation to participation in social movements, Gecas (2000) lists feelings of guilt as a manifestation of an individual member's value identity lacking congruence with that of the core group. In this way Anne's own behaviour has modified as a result of her involvement and she begins to take on more characteristics of the wider group.

So far, this chapter has reflected on consumer members' initial motivations for involvement, and factors that can be seen as contributing towards their continued involvement in research. In the next section, professional participants' motivations for involving consumers in research will be considered.

5.3. Professional motivations for involvement

In this section, interview accounts for involvement constructed with the professional participants will be explored. Specifically, having identified a number of initial and continuing consumer motivations for involvement based on life-world rationalisations, this section will examine how (or if) the professional accounts for involvement correspond with these.

Firstly, the interviews with the professional participants revealed that most were in favour of involving consumers in research in theory, but were yet to be convinced of the practicality of involvement. For example, Lisa (Chair, CSG subgroup) explained how she certainly welcomed the involvement of the public in principle, but that she felt there was still a lot to learn about the impact that they may have on the research process and outputs:

"So I think in principle public involvement can be very valuable. But I don't think we know anything near enough about what they might actually do and where they might be helpful, or where they might complicate things" (Lisa, Chair, CSG subgroup).

It was apparent that in principle Lisa was a supporter of consumer involvement in research. However, her comment that consumer members may 'complicate things' highlights, that first and foremost her primary objective is to produce research and, as such, instrumental rationality was often regarded as preferable to engaging with life-world perspectives. For example, Lisa went on to explain that a consumer member may advocate for particular research based on their life-world experience, but this may conflict with the scientific evidence:

"...you can have somebody, and this happened in a very public forum not too long ago, you can have somebody who was offered a very advanced treatment which is known to work wonderfully in a small subset of cancer patients, some people respond but the majority of cancer patients are not going to respond to it. And there are real questions, certainly in terms of health economics and to a certain amount ethically because if you're going to give something to somebody and 10% of people are going to do really well, by definition 90% of people are going to suffer harm. So where do you set those parameters? And in a place where there needed to be a very balanced discussion on risks versus benefits we actually had a very powerful patient advocate who was saying, without any consideration for the other 90%, 'this saved my life. It's only because of this that I've been alive for the last two years, this is absolutely wonderful, the finance doesn't matter, every patient in the UK should be offered this

treatment.' And you could see she was a zealot because it had been so good for her. But she couldn't see the wider thing".

Therefore, Lisa's account raises questions about the epistemic claim for consumer involvement in research. This was an important issue and is explored in detail in chapter seven.

Lisa's account was illustrative of the professional participants who were convinced of the principle of consumer involvement in research but not of the practice, on the other hand, some of the professional participants appeared to be convinced of both the theory and the practice of public involvement in health research. In contrast, a small number reported negative attitudes towards consumer involvement in research. These motivations and associated attitudes will now be explored, by first turning to the governance motivators for involvement.

5.3.1. Lay/professional collaboration as good governance

From the findings, it was apparent that the primary motivating factor for professionals to involve consumers in research was to fulfil procedural aspects of a particular study. For example, involving consumers in research was related to good research governance. For example, Joanne (professional participant, CSG4) stated:

"I think that now with ethics submissions and patient information sheets, to have involved the consumer is definitely a big help. If you've got someone who can help you you're more likely to get something through first time rather than have it turned back" (Joanne, professional participant, CSG4).

In the extract above, Joanne identifies consumer involvement in research as increasing her chances of successful Research Ethics Committee submission. In stating that consumer involvement can be attributed to greater success in ethics applications, it appears that consumer involvement can be regarded as a form of instrumental rationality, helping to achieve success.

In a similar manner the quotation provided below, taken from an interview with Victoria (professional participant, LRP), supports this argument. Rather than identifying consumer involvement as useful for success with Research

Ethics Committees, Victoria highlights a further governance imperative for consumer involvement, that of research funding:

"So we've been made aware of the need, through erm, you know, we keep our finger on the pulse of what the government require of us and so on. And it appears that input from patients or carers is more or less a requirement now. And that you stand a better chance of being funded if you can demonstrate, or your intention, to have patients and carers at best as collaborators or that they are being properly consulted about bits of the study, for example patient information leaflets that sort of thing, that they will have experience of, or a different perspective than the researcher" (Victoria, Professional Participant, LRP).

From this, it was apparent that consumer involvement in research was regarded as providing a useful function in ensuring efficient and successful outputs with regulatory bodies. The two quotes provided above are indicative of general feeling amongst many of the professional participants' interview accounts. They suggest that the governance requirements, framing public involvement in research as 'good practice', provide a strong incentive for involvement. Moreover, it could be argued that they serve as a form of 'governmentality', providing a normative discourse by which researchers' govern their own professional behaviour (Thompson et al, 2009). Matthew (professional participant, CSG) built on this point by explaining that whilst he felt there was initially some resistance to consumer involvement amongst the wider professional groups, policy and research governance developments have contributed towards diminishing this:

"...at that time user involvement was just kicking off a little but because INVOLVE had been around for about four years, or you know their equivalent before they were renewed. And there was a lot of resistance then... But it was quite early days in terms of user involvement. I mean I know it's less than ten years ago but the thing I've observed over the 9 years that I've worked in a research capacity is that user involvement has come on tremendously, I mean astonishingly, particularly over the last 4 or 5 years...I probably think it's to do with the political climate... from 2000 onwards many of the Department of Health guidelines have been driven by patient engagement in consultation. So if you look at the NHS cancer reform strategy now, the one that's just come out, again it's very, the patient's voice is very important in that. But also you have documents like the 2005 research governance framework the revised edition which places user involvement centrally to, in terms of good research practice. So I think that has promoted a lot of interest in user involvement" (Matthew, professional participant, CSG).

However, it appeared that the political imperative to involve consumers in research was not received favourably by all of the professional participants. For example, James (professional participant, CSG1) identified consumer involvement as being 'politically correct':

"Well it's politically correct, we can tick the box and say we've had a, our committee has conformed according to the government, or Department of Health recommended guidelines, because I think they do request that you have a lay person. But whether it actually improves the quality of the committee I would question. I mean others will have a completely different view but personally I think it's been of very limited benefit because unless we're trying to do something completely outrageous which I don't think we are I can't really see how they would add" (James, professional participant, CSG1).

Accordingly, from James' account it is apparent that whilst he may be involving consumers in research or working with them in research committees, he is far from convinced of the value of involvement. Consequently, it would seem that he is able to meet the governance requirements for involvement without actually committing to the potential for consumer members to play a role, which is essentially a form of tokenism.

It was apparent that systems rationality and organisational commitments played a central role in professional participants' motivation to involve consumers in research. This was especially true of the professional participants involved within the CSGs, where consumer involvement was not a 'choice', unlike the professional participants who approached and worked with consumer members of the LRP through 'choice'. Interestingly, an interview with Matthew (professional participant, CSG) hinted at the potential for professional resentment against the organisational pressure to involve consumers. Whilst Matthew had provided me with an extremely positive account of his experience of consumer involvement during the interview, he later went on to tell me that should I interview him at a different time, perhaps when he was employed elsewhere, his attitude towards involvement may be very different. In the quotation below, one can clearly identify not just the structural boundaries that Matthew appeared to feel constrained by, but also the political and social boundaries:

"...there is a great pressure to say user involvement is fantastic. 'There is nothing wrong with user involvement at all, everything is rosy'. And of course there are problems and challenges that need to be managed. But there is a real difficulty in actually expressing

them... And there isn't really an equal platform to raise those concerns at an intellectual/academic level. Because you almost feel as if you're being naughty and it's going to be slammed down by actually saying it".

(Matthew, professional participant, CSG)

It is apparent that as with James, Matthew also associates a degree of political correctness with consumer involvement. Again, one can look to the concept of governmentality when reflecting on Matthew's account that he feels unable to critique the public involvement policy or raise any difficulties because he would feel 'naughty'. In this way, the discourse of public involvement in research has provided a normative rationale whereby involvement is automatically framed as 'a good thing'. To express concerns about this may be regarded as inappropriate behaviour.

However, whilst the governance imperatives were a primary motivating factor, some of the professional participants spoke of the direct contributions that consumers could make towards achieving maximum outputs in their research. These findings will now be considered.

5.3.2. Consumer involvement contributing towards research outputs

It was apparent that some professionals were motivated to involve consumers due to the potential impact that they could have on research outputs. For some professional participants this was directly linked to the type of research that they conducted. For example, Charlotte (professional participant, CSG1) and Nicholas (professional participant, CSG subgroup) stressed the centrality of consumer involvement to their work. In the extract below, Charlotte is talking about her particular research interests and why she feels that consumer involvement is a necessity in this field of research:

"Well I think particularly when it comes to the effects of treatment you've got to have patients involved. Because one of the people who's been helping is actually a carer, she had a son who had a [cancer type removed] tumour and so you know, they're able to help really prioritise and make sure that what we do, and our proposals, are what they feel should be something that we're addressing" (Charlotte, professional participant, CSG1).

Clearly, it would seem that Charlotte identifies an intrinsic value to consumer involvement in health research, stating that in her field of research involvement is a necessity. In particular, because Charlottes' field of research

is focussed on understanding the effects of treatments, it would seem that communicative rationality and developing an understanding of the patient/carer perspective plays a central role. Therefore, it would seem that for some types of research, particularly those that necessitate communicative rationality, public involvement is regarded as important.

More broadly, one further aspect of the 'procedural good' argument was that consumer involvement in research was believed to have a positive impact on clinical trials recruitment rates. For example, when asked about the impact that she thought consumer involvement had on her study, Louise (professional participant, LRP) stated that she felt they had helped with the recruitment strategy taken in the research:

"Ideally we felt that we wanted to recruit and interview in the time window before they [cancer patients] had their surgery, certainly before they had their surgery results, because at that stage you bring in things like 'well you know you need chemotherapy, and you might need more surgery, things aren't as good as you might have hoped.' So we wanted to try and keep that bit of decision-making in the patient pathway. So we were planning on approaching and recruiting very early. And they [consumer members] had an issue with that and they felt that it was far too early and there was too much going on. And we had a potential for impacting on the decision that was made and also the psychological discomfort that some people might experience, thinking well 'perhaps I haven't been given all the information I need to make this choice and perhaps I have been more guided than I want to be'. So they [consumer members] very strongly said you know 'we think that the patient recruitment process is wrong, we think that you'll do damage.' So, you know, we listened, we talked about it and we erm, as a result of their input into that, did a consultation exercise in the units where we were going to do the recruitment with women who were a little bit further on in their cancer journey, you know saying 'if we gave information at this stage what would you think about that?' And, you know, the consensus was there that it needed to be given slightly later. So they impacted on our recruitment pathway. They helped us to design our patient information leaflets and our patient approach letters. So the wording, paragraphs and all stuff like that, but mainly sort of wording really. And they changed what we'd written... I think we've got a richer study and I think our patient recruitment was better than it could have otherwise been and it caused less upset amongst the women that we were approaching. I think had we approached people when we had been wanting to that we might have had more people getting upset..." (Louise, professional participant, LRP).

It would seem that Louise makes three distinct claims for the impact that consumers can have on the research process. Firstly, she describes the study as 'richer', although in what ways the study became 'richer' on account of

consumer involvement is unknown. Secondly, she directly relates consumer involvement with enhanced participant recruitment. As part of this, her third claim is that by involving consumers in research the study was more sensitive to the research participants.

Amongst other professional participants' accounts, there were claims that consumers could act as supporters and advocates for clinical trials. It appeared that this was often related to a perception that in turn consumer support for research may encourage a wider patient populace to take part in clinical trials. As Karen (professional participant, CSG3) stated, "*they are the main people who can pass on the message*", with 'they' being consumer members of the CSGs. Consequently, some professionals were motivated to involve consumers in research as a way to normalise, or promote public awareness and acceptability of clinical trials more widely. For example, Joanne (professional participant, CSG4) highlighted this idea:

"I would like to see it that when we see patients they demand clinical trials because they know it's a good thing. So education of the public, media awareness would be a huge bonus for us..."

Consequently, it seemed that many of the professional participants identified a functional role for the consumer - ensuring that the goals of the organisation (such as increasing recruitment into clinical trials) are met. In this way, the practice of consumer involvement in research may be regarded as a form of strategic action, which involved the consumers fulfilling a specific function within the overall aims of the organisation and helping to achieve research outputs.

The next section will turn to a further motivating factor for consumer involvement in research that was identified within the professional accounts. In particular, the next section concerns the potential for consumer members to contribute a degree of 'reality check' to research.

5.3.3. Reality check

The findings suggest that for the majority of participants who were in favour of involving consumers in research, their motivation was often due to a belief that consumer involvement improved the acceptability of a research proposal

and had a positive effect on the process and outcome of a project. For example, for Lisa (Chair, CSG subgroup), improving the acceptability of research was seen to provide some degree of 'reality check' - reminding professionals of the ultimate recipients of their work. From the quotation below, it would seem that Lisa constructs 'reality check' as ensuring that research can be clearly understood by, and has resonance with the wider public and the target population. This was an argument that was found in many of the interviews with the professional participants:

"I: So what do you think that they [the public] specifically bring to the group? Are there any qualities you can identify?"

P: I suppose a reality check and that kind of [you] don't get all hung up in jargon, make sure you've got a really clear question, making sure you can write down in quite simple language what it is you're trying to find out" (Lisa, Chair, CSG subgroup).

The 'reality check' role of the consumer in research was also asserted by Steven (professional participant, CSG4). However, Steven constructed 'reality check' as providing balance to the professional group. This is perhaps more suggestive of the consumers playing an ethical watchdog role:

"I see them probably more as a part of a checks and balances rather than a, because they obviously don't have the specialist knowledge or the knowledge of new treatment they are unlikely to be part of the initiation of a process. But I see them as an important part of the, an important check point that the proposed trial should go passed, on the 'is this reasonable?', 'is this a fair question to present to somebody?' sort of level. So I think it's essentially a slightly passive role. But that's not to deem that it's unimportant" (Steven, professional participant, CSG4).

The idea of a 'checks and balances' role has potential undertones of the type of 'tokenistic' working practices that some of the literature is highly critical of (Smith et al, 2006). The above quotation suggests that Steven perceives consumers as playing 'a slightly passive role'. Accordingly, consumer involvement could potentially be reduced to consumer consultation, with the role of the consumer in research decision-making groups redefined to that of validation or legitimisation of an existing project, goal or set of working practices. Therefore, far from providing an *epistemic challenge* to professional knowledge, consumers are potentially part of the research decision-making arena to agree (or disagree) with an existing course of action. Following this, the ultimate control of the research project, or the decision-making process and/or the outcome of research could be

maintained by the professional. In this way it could be argued that the consumer role in research decision-making committees may essentially become redundant. This will be explored in more detail in the next chapter (Chapter 6 '(Re) integrating the life-world').

The next section will reflect on one final theme concerning motivations for involvement. Specifically, the next section will consider the consumer role in advocating for research. It appeared that both consumer and professional participants' provided this motivation for involvement and it is therefore considered to be a collective motivation for involvement.

5.4. Collective motivations for involvement: embodying the advocate

From the findings it was apparent that within a couple of the CSG case study groups some professional and consumer participants constructed the consumer member as fulfilling the role of an advocate (an advocate for research). Specifically, this argument was found to be most prevalent amongst the rarer cancer groups, therefore CSG3, CSG4 and the CSG subgroup. As already speculated, this may be due to the specific type of cancer that these groups represented. Arguably, amongst these groups there appeared to be, what could be termed as, a 'struggle for visibility', within the research community, the NCRN, or research funding bodies. This appeared to contribute towards a greater sense of collective identity.

The 'consumer as advocate' model can be seen as a motivation for collaboration, facilitating the achievement of both system and life-world aims. For example, during the interviews with consumer members from the rarer cancer CSGs, there appeared to be a particularly strong emphasis regarding an apparent information deficit. This can be seen in the quote below given by Shirley:

"...as a group of course they are quite a large group, but we knew nothing. Of course you weren't given enough information, and we were scratching about for information. It was horrendous. I found very soon that there was no research into [these types of] cancers. When the [specific name removed] CSG started I think there were 2 research projects in the portfolio. And I think now there must be about a dozen. And this motivates you because this is going to improve the treatment" (Shirley, consumer member, CSG subgroup).

It could be argued that becoming involved with research decision-making groups helped to remedy patients' and carers' verbalised lack of information by integrating them within a group where the latest information and research technologies were readily discussed and debated.

Furthermore, as part of the 'consumer as advocate' model, patient/carer rationales sometimes corresponded with professional motivations. In particular, as already discussed, consumer advocates for research were seen to play a role in helping to increase recruitment rates to clinical trials. For example, during one meeting of CSG3, one of the consumer members, Alan, was observed to clearly align the patient role with '*increasing patient participation into trials and banging the drum for research*'. This was further emphasised during an interview with the Chair of CSG3, when he was forthcoming in his opinions about the benefits of working with patients and carers as advocates:

"...they've been able to apply pressure at various sources, to make trials come about where pressure from doctors themselves may not actually have been so successful. I'm talking particularly about [name removed], who you may know, who's on our group, who has really been very forceful at getting various things through various committees, simply because he is a consumer" (Peter, Chair, CSG3).

Consequently, the 'consumer as advocate' can be viewed as a role that helps to fulfil both professional and patient/carer objectives. It seems possible to claim that consumer membership of the CSGs operates as a form of strategic action on the part of the wider professional group, helping to realize systems imperatives. In addition, as has been shown, accomplishing systems aims was also viewed as beneficial by the consumer members as they are the ultimate recipients of research.

5.5. Summary of chapter

In this chapter, I have explored consumer and professional motivations for consumer involvement in research. I have highlighted the importance that consumer members appear to place on regaining personal control and using their experiences of ill health, treatment and care (good, bad or indifferent) to bring about some form of positive outcome or change. Furthermore, consumer participants suggested multiple constructions of involvement that appear to correspond with (and emphasise the multifaceted nature of) the

discourse of empowerment. I have also illustrated the emerging collective group identity that can be found within the cancer consumer group, based on life-world principles.

The chapter has indicated that professional motivations for involving consumers in research decision-making spaces vary. Some professionals appear to be primarily motivated through governance – or systems - imperatives, whilst other professional participants were seen to appeal to the value of consumer knowledge in providing a sense of 'reality check' or as custodians of ethically acceptable practice. Finally the concept of the 'consumer as advocate', constructed as a motivation for consumer involvement by both professional and consumer members, has been explored. Here both consumer and professional participants constructed this form of involvement as meeting systems and life-world orientations to varying degrees. The 'consumer as advocate' primarily fulfils systems objectives, such as increasing clinical trials recruitment rates and funding. Yet, it also appears that embodying the advocate enables the consumer to engage with expert systems in order to fulfil personal objectives; such as remedying a perceived information deficit.

In the subsequent chapter, the practice of consumer involvement in research will be explored. Building on the motivations for consumer involvement that have been explored in this chapter, chapter six will consider whether the voice of the life-world is integrated into the work of the case study groups and if so, in what ways. .

Chapter Six

Integrating the voice of the life-world into health research?

6.1. Introduction

In the previous chapter, the findings pertaining to consumers' initial involvement in research and factors contributing towards their continual involvement in research were considered. As a starting point, when reflecting on their involvement in research, the majority of consumer members began by disclosing information regarding their initial diagnosis of cancer, or the diagnosis of an individual for whom they were caring for, illustrating the centrality of their illness experience. In terms of their motivations for involvement, it was argued that consumers' experiences of health care services and treatment (good, bad or indifferent) were fundamental to their desire to 'give something back' or improve service provision for others. However, ambiguity over how this intended impact might be achieved was apparent.

It was argued that consumer members' continued involvement in research was constructed around involvement activities providing a proxy for aspects of their lives that had been altered due to their illness, for example career, hobbies and social networks. Furthermore, chapter five suggested that amongst the core group of involved consumers in the NCRN, there is an emerging collective identity. This collective identity appears to attract particular 'types' of consumer (professional backgrounds, civic interests etc) to involvement in research, whilst also providing a sense of belonging for the involved consumers and can thus be regarded as a motivation for their continued involvement. Consequently, it was apparent that consumer member's motivations for initial involvement, and their continual participation, in research were primarily located in the realm of the life-world. As such, their motivations appear to be located within processes of sense-making and "*the harmonization of individual biographies with collective forms of life*" (Britten, 2008; 18).

In contrast to the consumer motivations, professional motivations for involving consumers in research were found to largely centre on consumer membership fulfilling a functional role in research as part of wider organisational objectives. For example, professional participants spoke of the consumer role in ensuring the acceptability, applicability and feasibility of research. It was suggested that these motivations are primarily located within systems rationality and material reproduction, with consumer involvement aimed at achieving more efficient and effective research outputs through enabling increased recruitment to clinical trials and, more broadly, the normalisation of clinical trials within the wider patient population.

As a result, these somewhat contrasting motivations for involvement lead to questions about the potential for consumer involvement in health research to provide a space for a deliberative ideal and the integration of the consumer voice into research decision-making. In order to further explore these questions, the purpose of this chapter is to consider the data relating to the practice of consumer involvement in research.

Taking the CSG and the LRP case studies in turn, this chapter will begin by exploring the documentary and interview data concerning the organisational commitment to involving consumers in research. Following this, findings from the observational and interview data that highlight the practice of consumer involvement, and the role and place of the life-world within the case study groups will be explored. As part of this, data indicative of life-world integration, along with examples of visible and latent manifestations of power that serve to block or subvert the integration of the life-world in the case study groups will be considered.

Accordingly, it will be argued that there are stark differences between each of the case study groups in the way in which the consumer role and voice is facilitated, with some emerging tensions between systems and life-world aims within the groups. In the light of this, the findings presented in this chapter raise questions concerning the integration of the consumer voice in research.

6.2. Organisational commitment to involvement within the CSGs

In this section, the documentary and interview data regarding the organisational commitment to public involvement in research will be explored. Many of the 'newly' available deliberative spaces in healthcare which consumers are now involved in are primarily groups that have been established, and attended, by health professionals and researchers. The Clinical Studies Groups (CSGs) are no exception. As outlined in chapter four, the CSGs are the primary sites for the development of national cancer clinical trials, funded through the NCRI partner organisations (government, medical charities and industry). Fundamentally, with their emphasis on the development of research, the CSGs can be seen to be orientated towards instrumental rationality and systems goals. In terms of consumer participation, the CSGs are effectively operating as 'invited spaces'¹, with consumer membership the result of a wider organisational commitment to public involvement in research. For example, the NCRN website provides a clear endorsement of consumer membership:

"The NCRI and NCRN believe that by working with consumers the quality of research can be enhanced for the benefit of patients and the public".

The above statement frames consumer involvement in the NCRN as a quality issue and, as such, is consistent with the wider government claim outlined in the literature review that the public can directly contribute to improving the quality of research.

The written role description for the consumer members of the CSGs and the respective subgroups, states that one of the main responsibilities of a consumer member is to provide a consumer perspective. This can be seen in the extract below taken from the consumer member role description:

"Assisting the group(s) in understanding some of the perspectives of patients and the public that are relevant to the work of the group"
(NCRN Consumer role description and person specification, 2008).

Whilst lacking clarity, or specificity, the above extract appears to outline a basis for the integration of consumers' life-world perspectives. Interestingly,

¹ Taken from 'the power cube' as devised by Gaventa (2005) and discussed in the review of the literature.

the NCRN consumer role description refers to *'understanding some of the perspectives of patients and the public that are relevant'*, so one may interpret the consumer contribution as essentially managed by what is institutionally and professional defined as relevant. The CSG may choose to listen and/or incorporate consumer perspectives dependant on whether the group members' perceive the perspectives to be useful or valid. This appears to conceptualise a rather passive role for the consumer member.

Contrary to the official written consumer role description, a member of the CSG Secretariat, Helen, conceptualised the consumer role in a more active manner, emphasising the place for life-world perspectives in *challenging* professional opinion:

"So I think the consumers have a role in challenging the type of questions, whether it's an appropriate one, what are the benefits for consumers. You know whether it's the right study questions and whether it's relevant to consumers themselves" (Helen, CSG Secretariat).

Helen's construction of the consumer role moves beyond the official organisational policy of assisting the group to understand some of the consumer perspectives, towards a more active and assertive role in 'challenging' the work of the group. Helens' construction of the consumer role in research in challenging professional perspectives appears to be in accordance with constructions of lay health knowledge discussed in the literature. For example, Williams and Popay (1994) suggest that lay health knowledge provides a political challenge to the *'institutional power of expert knowledge in general'*. Furthermore, it appears that Helen's construction of the consumer role gives greater legitimacy to the voice of the life-world. Yet, whilst Helen appeared to provide a clear rationale for consumer membership of the CSGs, consumer members themselves frequently expressed frustration at the restricted nature of their contribution and their inability to impact on many of the decisions that were made within the groups. For example, Sandra explained that most of the research projects that she came across were essentially 'done deals', limiting her ability to play a meaningful role:

"...you're looking at almost done deals. Everything is more or less fait accompli" (Sandra, CSG2).

This point was reiterated by Liz (PPI lead for the NCRN), who acknowledged that consumer involvement in the CSGs could be restricted due to some of the projects that are brought to the CSG meetings being almost complete:

"You know the CSGs are the places where ideas for new trials are developed and discussed and so on. But often when they [consumers] get to those groups the trials have already been discussed or decided so there is a limit to the level of involvement. So yes they [consumers] are sat on those panels but there are only particular parts of the process that they will be involved in by virtue of that arena" (Liz, professional participant, CSGs).

Liz's acknowledgement that the consumer members will only be involved in *particular parts* of the CSG meetings again suggests that the consumer role is potentially restricted to what is institutionally/professionally defined as relevant. These restrictions may limit the potential for consumer members to challenge the professional discourse. Furthermore, the possibility that the consumer role is restricted to checking 'done deals', would suggest that communicative rationality would be unlikely to occur. In order to explore this further, in what follows the observational and interview data pertaining to the practice of consumer involvement in the CSGs will be explored.

6.3. System/life-world integration in the Clinical Studies Groups (and subgroup)

The observations of the CSGs revealed that the structured format of the meetings appeared to restrict the potential for the development of in-depth discussions and shared understanding. From the observations it was apparent that the CSG meetings are governed by a normative framework of operation. To this end within each group there is a focus on group members providing updates on clinical trials accrual rates, targets and outputs of existing projects, and discussing the feasibility and validity of newly submitted projects. Each CSG follows a standardised agenda (see appendix E). In this respect, arguably all members (both consumer and professional) are somewhat restricted in their ability to influence the pre-established agenda that is followed throughout the meetings and the focus is firmly rooted in achieving outputs. Some of the consumer members, also recognised this restriction within the CSG meetings, with Hannah (patient, CSG4) talking about the 'quick pace' of the meetings, whilst Ruth (patient,

CSG3) appeared to rationalise the systems orientation of the meeting. In the quotation below Ruth is talking about her reflections of how CSG3 worked together as a group:

"I think on the whole it does work. It's just they have so much to do and so little time, you really feel the pressure on people to get through the agenda and peoples' frustrations at things that haven't moved forwards from the last meeting and stuff like that" (Ruth, patient, CSG3).

Members (both consumer and professional) are assigned a specific slot on the agenda during which they can update the wider group on any issues that they feel are pertinent. For example, the 'Report from the Consumer Representatives' is always item 5 on the agenda (about halfway through), having been somewhat symbolically moved up from the penultimate item on the agenda. When questioned about this, Helen (CSG Secretariat) explained that this had been done in order to give the consumer members a '*higher status*' on the agenda, clearly associating their symbolic place on the agenda with their relative importance and attempting to prevent consumer issues being viewed as an 'after thought' or an 'add on':

"I think when I originally started this job, I don't even think a standard consumer item may have been on the agenda. Then it got onto the agenda and it was always put at the end. Then I said 'no no you can't do that'. So we've moved them up the agenda ... So it's trying to given them that sort of status" (Helen, CSG Secretariat).

Yet, regardless of the official consumer placement on the agenda, during the data collection I observed inconsistencies between each of the five CSG case study groups in the apparent 'status' afforded to the consumer agenda item. For instance, there were apparent differences in the timing of the consumer agenda item. This was observed during data collection with CSG case study group 1 (CSG1) when the consumer item was (in the words of the Chair) '*slotted in just before lunch*'. The findings also pointed towards disparities in the way that some CSGs seemed to respond to consumer members' input into the group discussion. Subsequent sections will explore some of these key areas of difference in approach that were found within the CSG case studies. Turning first to the use of technical language and acronyms, the next section will consider the way that language can be considered a barrier

to achieving communicative rationality and, as a result, the integration of the consumer voice.

6.3.1. Achieving understanding: acronyms and the use of technical jargon

The use of acronyms and techno-scientific jargon were found to feature heavily in the group dialogue. During the observations, I felt frequently lost in the technical language. Consequently, I experienced some empathy with how I believed that the consumer members may feel concerning the difficulties in following the meetings that some of them had told me about during the interviews. For example, in the extract below Fiona (patient, LRP & CSG) discussed her preparedness for the CSG meetings. Her quote is illustrative of the general feeling amongst the consumer members interviewed:

"You got this whacking agenda through the door and you looked at it and thought 'oh dear god, what does that say?' And a lot of it is very penful and urm the material that they get through in a day is absolutely staggering...and there's acronyms, so you spend your life going 'and such and such is?' and you're thinking 'and that is?' So it's quite technical" (Fiona, patient, LRP & CSG).

Fiona's account highlights both the quantity of material that the CSGs were charged with tackling during the meetings, but also the technical nature of the material. Furthermore, Fiona went on to explain that in spending a great deal of time interpreting the material for the meetings and trying to follow the discussion, the opportunities to contribute to the group discussion were seemingly limited.

Whilst some consumer members reported that they had received 'jargon busters' (lists of commonly used acronyms and definition of terms), the use of technical language within the CSG meetings appears to constitute a barrier between the development of shared communicative understanding, with several consumer members informing me at various points about the difficulties that they had in following the meetings (such as Fiona, above). The following extract from my observation notes of CSG1 is illustrative of this:

"During lunch, I chat with Anne (patient) to find out about how she is finding the meeting. She tells me that before she attended her first meeting she had been given a list of acronyms by the Consumer Liaison Group. However she says that she hasn't found these particularly useful as the meeting moves at a fast pace and a lot of acronyms that are used aren't on the list" (Observation notes, CSG1, April 2008).

From this it appears that the pace of the CSGs meetings, coupled with the partial list of acronyms contributed towards the difficulties experienced by some consumer members. However, James (professional participant CSG1), suggested that these barriers were not unique to the consumer members of the CSGs. James explained that different members of the CSGs have expertise in different specialist areas and therefore may not be fluent in all aspects of the meeting. James likened this to the difficulties experienced by consumer members in following the meetings:

"I think initially when we first started having lay members I wondered whether it would have a negative impact, having the presence of somebody who doesn't have the same knowledge and scientific background might have an inhibiting role. But in fact I think now we're relatively used to that and people just talk as though they are full members and have full knowledge. That's the other thing, other members of the committee will have different levels of expertise, so I could be talking about a clinical trial but a radiologist or pathologist may have relatively limited knowledge about that particular trial" (James, professional participant, CSG1).

Following James' argument it appears that an ideal speech situation, as proposed by Habermas, would be an unlikely outcome of the CSG meetings. Moreover, it would appear that there is an acceptance that not all members can, or indeed should, understand the content of the meeting.

In contrast to James' account, the findings indicated that in some of the CSGs there were efforts to facilitate the active engagement of the consumer members. For example, within CSG3 my observations highlighted a clear attempt by the Chair, and other professional members of the group, to explain technical aspects of research studies and clinical trials in 'plain' English. Included in this was the group tendency to use the full titles rather than rely on acronyms and to explain the meanings of specialist terms, in comparison to the other CSG case study groups. This behaviour was also observed (although to a lesser degree than within CSG3) in CSG2 and CSG4. Furthermore, I observed the Chair of CSG3 explaining discussion points in

more detail, directly addressing the consumer members. As an observer, this did not seem to be detrimental to the group interaction, or the general flow of the meeting. Rather, it gave the impression of a commitment to shared communication and inclusivity, ensuring that consumer members understood technical aspects of the meeting.

These observations were strengthened during an interview with the Chair of CSG3. When asked about any potential challenges he had encountered from working with consumer members in the CSGs, he highlighted his responsibility to make sure that the consumer members were always able to follow the group discussion:

"Er, well I think we've got to make sure our discussions are comprehensible for them and we're not getting carried away with political stuff within medicine and terminology. We've got to make sure that the language we use is understandable to them as well. And certainly if I think something is a bit esoteric is being discussed in our group I would normally stop and explain it. At least I hope I would" (Chair, CSG3).

Yet, whilst this seemed to be illustrative of attempts to achieve shared understanding within the group, notably this appeared to be weighted towards consumer understanding of the technical world, rather than professional understanding of the life-world. In this way, systems aims were explained in order that they may be considered as acceptable. Nonetheless, within CSG3 there seemed to be a general sense of mutual benefit and cooperation between the consumer and professional group members. This may be partly attributable to the limited membership of the group, with CSG3 being the smallest (in membership) of the CSGs included in this research. It was also a group that represented a rare form of cancer, one that is apparently underrepresented in the general cancer research portfolio within the UK². This certainly appeared to contribute towards an impression that the group was open to cooperative working, underpinned by a shared sense of unity, in group members' efforts to increase both public and political awareness of the visibility of this type of cancer (as discussed during chapter five). The extract below, taken from an interview with one of the professional participants of CSG3, illustrates this point:

² In comparison, for example, with more widely publicised breast cancer and skin cancers (Gerlach et al, 1997), or more prevalent breast and bowel cancers (Cancer Research UK, 2008).

"In [cancer type removed] because it's a small group ... they get to know each other and they share their experiences and I think that's an important thing, especially with these rare cancers...As I say it's a close group as a result of not having many patients" (Karen, professional participant, CSG3).

There were further instances of, what I interpreted to be, overt efforts to ensure consumer understanding of the clinical/technical aspects of the discussion within the other CSGs. For example, during observation of CSG2, the Chair interrupted one of the professional member's during his agenda slot, in order to request that he refrain from using acronyms. The professional member in question readily turned to the consumer member and explained the information in more detail:

"One of the professional members updates the group on the trials accrual rates. This exercise takes the form of a list of trial names, usually in acronym form, and the number of participants currently recruited to the trial versus the number of participants needed for the trial. It is fairly fast paced and I find it difficult to follow. As he is doing this the Chair interrupts saying 'I'm aware that we're using acronyms' asking that there be more explanation of these for the benefit of the consumer members" (Observation notes, CSG2, July 2008).

Again, these observations confirmed the central role of the Chair in maintaining group integration. Building on this, Shona (professional participant CSG5), told me about how the Chair of CSG5 was instrumental in ensuring that the professional members were reminded about their use of professional jargon:

"There's usually about 20 of us and if one turns up, there's one consumer and I'm afraid very quickly as far as I'm concerned, we forget if someone doesn't know our jargon if you like. Our Chair is good at reminding us" (Shona, professional participant, CSG5).

The above extract indicates the orientation towards systems talk and the necessary role of the Chair in facilitating a turn towards forms of communicative rationality. This behaviour was also observed of CSG4 where one of the professional members and the Chair openly encouraged the consumer members to speak out freely in order to seek clarification on technical terms:

"The Chair calls the meeting to order and swiftly moves onto the action points from the last meeting. One of the points is with regards

to a list of acronyms for the consumer member. Steven (one of the consumers) says that they have received them and they have them in front of them but at the speed that the meeting moves it can be fairly difficult. One of the professional members (female, 35-40), sat a few places away from Steven, says that if they need any clarification they can ask her. The Chair also agrees with this point, saying that they should speak up if they don't understand something" (Observation notes, CSG4, September 2008).

Accordingly, from the findings it would seem that there were efforts within some of the CSGs towards achieving some commonality of understanding. Although, as already stated, it appeared that this was primarily located in communicating the technical/scientific aspects of discussions to the patients and carers in order to enable their understanding of the scientific world, rather than the patient/carer explaining their perspective, or life-world experience to the professional members. This potentially implies that some CSGs rely on a one-way transfer of knowledge rather than a commitment to understanding the perspectives of consumer members, as the NCRN policy commitment would suggest. Accordingly, within some CSGs consumer involvement is more about letting consumers see the experts at work rather than *"opening up expertise to new questions and perspectives"* (Stilgoe et al, 2006; 19).

In order to further explore this, the next section will turn to reflect on the data concerning the contributions that the consumer members made within the CSG meetings and the observable interactions between consumer and professional group members.

6.3.2. Consumer contributions to the CSG meetings

Given the policy claims that public involvement in research entails a broadening out of deliberative spaces and the integration of 'different perspectives', the observable contribution of consumer members to the group meetings is important. Whilst the observational data of the CSGs are restricted to one meeting for each of the five main groups and two meetings for the subgroup, within these meetings I interpreted examples of constructive professional and consumer interaction and exchange, and examples when this interaction did not appear to be very constructive. Certainly, within some of the CSG case study groups I identified both overt and subtle strategies that appeared to prevent the incorporation of the

consumer voice into the meetings. Some of these data have already been discussed in the previous section and further findings will be explored in section 6.3.4. However, there also appeared to be examples of a commitment towards communicative rationality and integrating consumer perspectives into the meetings. These examples will now be considered.

Out of the CSG case study groups, CSG3 appeared to typify one case where I observed a consistent level of interaction between the professional and consumer members of the group. Throughout the meeting, issues that were raised by the consumer members were observed to generate wider group discussion. There was an impression that the professional members afforded some value and credibility to consumer membership. This was inferred from my observations including; the professional members asking questions of the consumer members, verbally stating an interest in what the consumer members were saying, appearing to listen (by watching the consumer members during their update and making verbal ('hmm' and 'yes') and non-verbal signs (nodding, smiling etc.)).

The extract below, taken from my observational field notes, is illustrative of this interaction and the integration of the life-world. It documents my interpretation of one particular occurrence of patient/professional interaction and exchanges during the consumer agenda item of the meeting:

"Ruth (consumer member) reads out a written update that she has prepared about two patients she had recently met and the difficulties that they had experienced in getting a diagnosis. This appears to prompt the Chair, as he chips in saying that he is about to start a project concerned with raising awareness amongst GPs about diagnosing [specific cancer type removed] ... Hazel (consumer member) is next to speak. She thanks the group for letting her be there. She tells them how she has had a fear of GPs but only recently, two years later and after coming to the CSG meetings is she 'over it'... Hazel then says 'I'm here, I have a perspective so use me if I can help you'. One of the research scientists adds in here, 'talking of perspectives...' saying that he is interested in finding out what happens with regards to patient and professional experiences of diagnosis in other centres. Hazel responds, by talking about the difficulties that she had encountered in getting a diagnosis and how she feels partly responsible for not 'badgering' her clinicians. She is quite emotional about this and looks like she is welling up. One of the biostatisticians responds to Hazel's story by looking to the Chair and suggesting that this is perhaps an area where they can potentially roll out their awareness study, to which the Chair agrees" (Notes from observations of CSG3, 22nd May 2008).

This extract is illustrative of the interplay between the voice of the consumer members based on communicative rationality, and the systems, or research outputs focus of the professionals in CSG3. Within this particular case study group, the voice of the life-world (in the case above, Hazel's perspective) appears to complement, or work alongside, the professional 'outputs' focus, with patient experience prompting, or strengthening ideas for research.

Outside of the main CSG groups, given that the CSG subgroups are cited as one of the primary routes for generating new research and developing ideas within the NCRN (NCRN, 2008), one could assume that the incorporation of the consumer voice at this more 'discursive' level of research would be fundamental to the NCRN in realizing their stated commitment to consumer involvement. From the findings it would seem that the subgroup case study supported this. For example, the Chair of the case study subgroup was observed to repeatedly consult consumer members for their opinions and suggestions during group discussion, often seeking out confirmation regarding specific patient related issues. For instance, at one point the Chair asked one of the two consumer members, Shirley (in her role as a carer and the Chair of a large patients' forum), to provide feedback concerning financial and communication issues affecting patients. At other times within the CSG subgroup, the consumer members freely contributed towards group discussion (seemingly without restraint) and on a number of occasions professional members were observed to openly acknowledge consumer member contributions to research funding bids prepared by the group. This all contributed towards a feeling that the group operated on a fairly inclusive level. Certainly, the interviews conducted with the Chair, one professional member and the two consumer members, appeared to substantiate this and there was an expressed mutual regard for members roles. During an interview with Nicholas (professional participant, CSG subgroup), he explained how the involvement of patients and carers in his work was fundamental:

"Well I think it's quite easy from my perspective because all my work is driven towards trying to improve patient outcomes, driven at a clinical level. I'm not a microbiologist or a molecular oncologist or anything like that. So if you're trying to improve patient outcomes and patient experience and carers, without involving them you're not going to get very far. So it really reflects my interest in terms of what

I am trying to do for patients, the health service, what drives me to try to improve patient care and experience and to do research regarding those aspects to really give validity and make changes in practice robust and defensible”.

In the extract above, Nicholas links his research interests with his inclination to include the consumer voice in research. Nicholas appears to assess the relevance of the consumer voice in other forms of research, seemingly discounting the applicability of involvement in biomedical or laboratory based research. As Nicholas’ research is centred on patient outcomes and the patient experience, the patient voice is regarded as fundamental to this work.

Similarly, the Chair of the group identified a clear impact resulting from consumer involvement:

“Interviewer: *I wondered if you could tell me what impact involving lay people in research has had?*

Sheila: *It changes it quite profoundly. It’s probably, easy is not the right word, but it’s probably really important in the kind of work that I’m doing on communication because communication has to be a two way process. And it’s been difficult in the past to actually get together with a defined person and say ‘if I were to ask these question would people understand what I’m asking?’ And now we’re in a position where we can sit down together and we can talk about the kinds of information we want and then we can phrase the questions together to get it right...But I do think that they’ve had a real change and very much on the interface, very much bridging the gap between the professionals and the study participants. That’s probably where the main impact has been” (Lisa, Chair of CSG subgroup).*

Sheila’s suggestion that the consumer members ‘*bridge the gap between the professionals and the study participants*’ is perhaps indicative of consumer involvement providing a link between systems and life-world knowledge. Thus, whilst the observations of the CSG subgroup highlighted that the development of a communicative discourse was ultimately restricted, on account of the technical/systems orientation of the CSG meetings, the professional participants seemingly valued consumer input.

Consequently, this section has identified some examples of what may be regarded as constructive interaction between the professional and consumer members of the CSGs, with distinct consumer contributions to research identified. Within all of the CSG groups the overall discourse and the content of the meetings are managed by the Chair but are ultimately in line with the

organisational function and remit for the CSG groups. In this respect, it could be argued that the ability for any member (consumer or professional) to transform the content of the meeting will always be severely restricted.

6.3.3. Physical presence

Regardless of an observable verbal contribution to a CSG meeting, it was apparent that for some of the consumer members their contribution to research decision-making groups was simply their physical presence at the CSG meetings. For example, it was suggested that by their very presence in the room, consumer members were acting as a reminder to the professional membership, concerning research participants and the end users of research. The quotation below by Ben (patient, CSG4) is illustrative of this:

"I think it's a physical presence so the professional members are aware that there are consumer members and I'm one of them. And I think the benefit of that is that when making decisions or having discussions your physical presence is a reminder of what it is you're actually aiming towards, which is about finding cures for cancer if you like, to reduce it to a simple level and that's about people. I think also from experience, what that also does is reminds people to use appropriate language sometimes in explaining things. And I think it can also have an impact on behaviour" (Ben, patient, CSG4).

From this, it could be argued that Ben appears to readily identify himself as occupying a slightly passive position within the group, one that is reliant on professional members acknowledging and acting on his presence. Accordingly, one may infer that he prescribes a certain degree of faith or trust in professional conduct. Mary (patient, CSG) built on this point:

"I think what surprised me was that other people there were more willing to take notice of consumers that were sitting there. You know, really listen to us. And I think I hadn't expected that... You know there's odd occasions when you've gone to a meeting and you've not being able to contribute much and then you think 'oh I didn't feel very useful there'. But then some people say to me 'well actually it changes the tone of the meeting, the fact that you are sitting there'" (Mary, patient, CSG).

The claims, made by both Ben and Mary, indicate a construction of the consumer role in providing a moral filter to research. The argument appears to be that consumer presence in the meetings has an impact on professional behaviour. This is quite a sizeable claim, particularly given that the idea of

consumer members having a direct impact on professional behaviour and attitudes was only suggested by a small number of the professional members. For example, Joanne (professional participant, CSG4) referred to the consumer presence as providing 'a useful jog'. A suggestion that is seemingly inferior to those accounts provided above by both Ben and Mary. Furthermore, other professional participants disputed the consumer argument concerning the impact of their physical presence. For example, Shona (professional participant, CSG5) commented:

"I would question whether their physical presence in a meeting is a good use of their time".

In this way, it was apparent that the consumer and professional constructions of the consumer role were often disparate. Building on this, the next section will explore how the 'physical presence' of a consumer member could often be discounted or discredited within the CSG meetings, reinforcing consumer passivity and leading to questions about their role within the group.

6.3.4. Discounting the voice of the life-world – mechanisms of power

Whilst the previous section has provided some examples of what might be classed as 'positive' interaction between professionals and consumers in the CSGs, the findings also indicate that within some of the CSG groups the potential for consumer participation was somewhat limited. At times this was inferred from the seemingly low status afforded to the consumer agenda item. For example, the consumer agenda item in CSG1 was slotted in 10 minutes before the meeting concluded for lunch. In this case, the meeting was already running 15 minutes behind schedule and the lunch had been laid out at the back of the room. This contributed towards a hurried feeling during the consumer update, and to a general impression that the consumer update was perhaps of less importance than other agenda items that had been given more time.

A further example illustrating the limited role of the life-world in research was found during observation of CSG5. Theoretically, whilst the consumer members are all entitled to contribute to group discussions (as with any other group member) this was not what always appeared to happen. The extract below is taken from my field notes during my observations of a CSG5

meeting. It provides one example of when a consumer member endeavoured to bring in their experiential knowledge (thus fulfilling the consumer remit) by asking practical questions related to a particular clinical trial. From the extract below, one can see the way in which the consumer role (or life-world) is overtly blocked by the Chair:

"During the next item, which is a run through of trial accrual rates for clinical trials registered with the NCRI, I feel that Paul (lay member) wants to say something as he shuffles in his seat and appears to apprehensively, and very briefly, raise his hand. The Chair doesn't appear to notice this, however Dr. Jones who is sat next to the Chair whispers in the Chair's ear and points over to Paul, so I assume that she is informing him that Paul has something to say. This appears to prompt the Chair to ask Paul if he has something to say. Paul asks a question about one of the trial protocols that is attached with the meeting notes and begins to query the eligibility criteria for patient selection, asking for clarification about how these criteria were decided on. The Chair interrupts Paul as he is speaking saying "Can I not answer that now Paul? I don't want to take up the committee's time. I will address them at lunch if that's okay?" He goes on to explain that the trial is already up and running...Paul nods and the Chair moves onto the next item" (Observation of CSG5, May 2008).

What is made apparent in the extract above is the potential for a hierarchy of importance amongst the group members. In this case, Paul's credibility is clearly under question, as his input into the group discussion is dismissed as a hindrance rather than constructive to the work of the group. This example, whilst by no means representative of all the CSG case studies, certainly presents what appears to be an overt occurrence of distorted communication. Here, Paul's function within the group discussion is essentially limited within the confines of what the Chair reasons to be an acceptable contribution, at any given time. On this particular occasion, Paul's attempt to query the patient selection criteria is openly blocked by the Chair, thereby reducing the credibility of Paul's role in the group.

Drawing on Habermas' theory of communicative action, the above extract highlights how the action-orientated goals of the group are paramount. The life-world contribution is disregarded in favour of systems-orientated goals, aimed towards achieving action. In other words, Paul's attempts to achieve greater mutual understanding of a clinical trial research protocol are cut short, with preference openly given towards moving the meeting on. Here the consumer role is restricted within what appears to be a *fait accompli*. The preference to communication aimed at achieving action was further

reinforced during an interview with the Chair of CSG5 (Andrew). When asked about his understanding of the consumer membership of the CSGs, Andrew began by claiming that consumers have a role to play in all areas of the group, and that they provide *balance* to the functioning of the group:

“Interviewer: So what’s your understanding then of why consumers serve on the CSGs?”

Andrew: Erm, well it’s to, essentially it’s to input the view of the consumers into, across the board. So from potential research questions, areas, priority areas for research, right up through conceiving and designing studies, asking relevant questions, to balance the way the studies are designed and to improve the interpretation of the data. So it’s right across the board” (Andrew, Chair, CSG5).

However, as the interview progressed it became apparent that in actuality, Andrew (Chair, CSG5) perceived consumer involvement as secondary, or subsidiary to the outputs orientation of the group:

“I mean I have to say that involvement, that the involvement of the consumer representatives, is not at the top of the list of priorities at present...if you look at, sort of, what we’re aiming for, which is essentially delivering studies, bringing in income, bringing in industry sponsored studies, interacting with other agencies, advising NICE running study days. All of those and, developing the role of the consumer representatives isn’t at the top of those list of priorities. And when we get reviewed on a, every 3 years it’s one of the things that’s covered. But they will look at grant income, they will look at publications, they will look at percentage, number of patients in clinical trials before they will look at consumer involvement. And consumer involvement is, you know it’s a much softer end point as it were. So you can say, ‘yes we’ve got 3 representatives and if they were involved in all the study design and concept’ etc and that really ticks the box. I’m not saying that that’s right but, so we don’t have the same targets at least” (Andrew, Chair, CSG5).

Consequently, the argument regarding the structural constraints within the group appeared to be strengthened. The quotation provided above illustrates one example of how consumer participation can be downgraded in favour of wider systems orientated priorities.

In a similar way, whilst Matthew (professional participant, CSG) was actively involving consumers in research, he also identified structural constraints to effective collaboration. In the extract below, Matthew discusses the potential

that the culture of academic research might act as a barrier to effective involvement:

"...at the same time [as working on my current study] I'm working on the demands of the University, RAE for example, and the need to get on with the next study. And I'm having huge pressure at the moment picking up a new study, which also has user involvement in there... So still having to do user involvement activity of the previous study and actually I haven't got time to do that because of the pressures of taking on this new study. So that's a problem as well" (Matthew, professional participant, CSG).

Consequently, the academic environment might discourage communicative action, and effective consumer involvement in research, due to the pressure to produce material outputs, in the form of new research studies.

There were other examples within the CSGs that indicated more subtle forms of life-world obstruction. As already explored, the role description for the consumer members of the CSGs, outlines the consumer role in introducing the 'patient perspective'. Furthermore, the Secretariat expanded on this to include the consumer role in assessing the relevance of research from a patient and carer perspective. However, as a deliberative ideal, this was not always met. During an interview with one of the consumer members of CSG1, Anne (patient), she told me about an occasion when she felt that she had attempted to introduce her preferences as a patient to the attention of the group. The extract provided below, taken from an interview with Anne, highlights her reflections about the reaction of some group members' to an issue that she held in high esteem – complementary therapy. The extract begins as Anne is talking about impact that she feels she has within CGS1:

"I mean as it happened, I did have an impact in the first meeting, I did manage to say something which had an affect....It was someone on the agenda, and I can't remember who it was, it had something to do with the complementary therapies group and he asked did anybody want to go along to something that was happening with complementary therapies. And there was almost, you could almost describe it as a snigger went round. And it was so obvious that they dismissed it totally and nobody did want to go to this thing. So later in the meeting, the Chair, again doing a good job as a Chairman, turned to me, asked me to introduce myself to the group, which in itself was terrifying... And I, because I was feeling such a spare part at that point, I thought 'oh blow it! I don't care, even if I don't come again I'm going to say something'. So in this very peculiar voice that wasn't mine because I was so scared, I actually commented on the fact that I noticed the response to complementary therapies, and I

was surprised that there was so little interest because certainly from the patient's point of view and my experience with other patients, complementary therapy plays a very important role in the path of their recovery. And I think I said something like, something to do with the fact that when you've finished your treatment and you're just left to get on with it, there's a need for a lot of people to be proactive so they feel they're doing something to help themselves. And this is where I think that complementary comes in because people feel 'well I'm doing something to help myself' (Anne, patient, CSG1).

The extract provided above is illustrative of the feelings of intimidation that were associated with being involved as a consumer member of a CSG and attempting to introduce a consumer perspective, an issue that was raised by many of the consumer members during the interviews. In response to Anne's declared interest in complementary therapy, the Chair of the group made, what Anne felt was, an overt attempt to act on her behalf by inviting a speaker from a complementary therapies research team to attend the subsequent group meeting (at which I was present as an observer). From this, one could assume a commitment by the Chair to the value of consumer opinion and perspective, as Anne's interest appears to have generated an item for wider discursive engagement.

Yet, at the subsequent meeting, during which there was a presentation given by a member of the complementary therapies research group, I detected some animosity (in the form of sniggering and eye rolling) from a small number of the professional members of the group towards the visiting speaker, during her presentation. I noted how their behaviour and apparent disregard for the presenter had made me feel somewhat uncomfortable. During the interview with Anne (Patient, CSG1) she raised the incident that I had observed, asking me during our interview "*I think you saw the response at the second meeting when she [complementary therapies guest speaker] was speaking didn't you?*" Therefore, whilst the Chair of the group had taken some action to integrate one of the consumer member's interests into the wider group discussion, the disinterest displayed by a minority of group members appeared to prevent the development of group discussion and any effort towards achieving collective understanding, through communicative rationality.

Collectively, these findings, whilst illustrating the bounded nature of the consumer role, also provide examples of the subtle (and not so subtle)

mechanisms of power at work within some of the CSGs. Preventing a consumer member from requesting clarification of a point (as highlighted within CSG5) was illustrative of an overt assertion of the Chair's power over the consumer member in deciding what constituted a credible contribution to the discussion. Whilst undermining a patient preference (as seen in CSG1) was illustrative of a more subtle form of power exercised by group members.

The use of humour was found to be a further mechanism that may contribute towards reinforcing patient passivity within the CSGs. This was observed during a meeting of CSG1, when the Chair and a number of group members made, what I felt to be, inappropriate comments alleging the lifestyle choices of patients with a particular form of cancer. The following is taken from my observation notes of the meeting:

"A discussion breaks out between a couple of the clinicians about who sees which patients and about the new young people's centres where 18-25 year old [cancer type removed] patients are now sent. The Chair asks 'Is any of this relevant to this group?' to which one male clinician responds; 'Yes it's about us as a group of [cancer type removed] experts staying involved in 18 to 25 year olds care rather than someone else. The discussion continues with a debate about when a patient is classed as a child or an adult in terms of the health care that they receive. The Chair then makes a comment about teenage [cancer type removed] patients having 'been around the block. They've lived a full life and are definitely not teenagers.' Many members of the group laugh at this" (Observation of CSG1, April 2008).

These seemingly moral assessments were made whilst two consumer members (both patients) were present at the meeting. During an interview with one of the professional members who was present at the meeting, she reflected on the comments that were made:

"Some people can sometimes make comments based on stereotypes. I mean I'm just thinking about the last meeting where somebody had made a comment that really wasn't terribly fair and I'm not sure that's the right sort of thing to be doing in that sort of setting" (Charlotte, professional participant, CSG1).

Interestingly, Charlotte, as a relatively recent member to the group, professed to feeling restricted in her ability to challenge this dominant behaviour. This is perhaps illustrative of the hierarchical structures in place within the CSGs. Here, the dominant professional group were seen to be passing moral judgments on the patient group, reflecting a

professional/patient divide; in this case framing some patients as deviant by judging their behaviour. And whilst this occurrence was an extreme case within the findings, it does appear to highlight the active power differentials that are at work within the CSGs. Furthermore, the dominant professional group can be seen as extending their area of expertise beyond the remit of the group to make moral and value judgements. Hierarchical structures were also identified during interviews with other participants. For example, in the interview extract below, Joanne (professional participant, CSG4) can be seen to identify with the consumer members, in terms of feeling intimidated by other member's professional status and credibility:

"...it can be fairly daunting these committees, you know I'm very junior in my speciality and it's daunting enough for me to have all these professors and high flying big names and I think a patient if they were a shy and retiring type it would be quite easy to feel overwhelmed or feel that they couldn't interrupt something and ask why we're doing this or that" (Joanne, professional participant, CSG4).

Given that the CSGs are a largely male dominated environment, one might also speculate on the gendered nature of the power differentials at play. Essentially, far from achieving greater integration between the system and the life-world, the findings have illustrated that in some instances, a number of mechanisms are employed that appear to reinforce the existing identities of the patient and the professional.

6.3.5. Summary of life-world integration in the CSGs

The previous sections have explored the integration of the consumer voice, or the life-world, into the workings of the CSGs, and the subgroup. The findings have illustrated how the contribution of consumer members and the integration of the life-world within the case study groups was variable. Within some CSGs there appeared to be an identifiable contribution by the consumer members and a commitment by the wider group to the inclusion of the consumer voice. This was often found to be attributable to the example set by the Chair. Amongst other case study groups, there were examples that were indicative of a limited role for the consumer member and

mechanisms employed to block or undermine the voice of the life-world were identified.

In the next section the findings pertaining to the system/life-world integration in a local research panel will be considered. It is intended that in exploring the process of consumer involvement at a local level, along with the national level already considered, the different approaches may be compared and contrasted.

6.4. Organisational commitment to the LRP

In terms of Gaventa's (2005) concept of 'spaces for participation', the LRP can essentially be considered as a 'created space', rather than an invited space, as compared to the CSGs. The origins of the LRP are located in patient/carer mobilisation concerning a desire to assist researchers in their clinical research. In its infancy the LRP was a small ad hoc group, yet as it developed in partnership with an academic department it became increasingly structured. As such, the LRP provides one example of public involvement where both patients and carers have played an integral role from its inception. Accordingly, one might assume that the discourse within these meetings would be communication focussed – aimed at achieving a shared understanding between patient, carer and professional worlds.

As the panel has evolved, they have become increasingly organised. For example, 'terms of reference' for the operation of the group and a person specification have been developed by existing members of the panel in collaboration with the academic department (appendix F).

As previously outlined, the remit of the LRP is to coordinate consumer activity in research, in order that researchers have a central resource with which to engage with consumer participation. During the year in which data were collected, LRP panel members assumed a variety of roles ranging from; attendance and involvement at national and local conferences, involvement on national trial steering committee groups, through to working on local research projects as advisory group members, or commenting on patient information sheets and undertaking a consumer led piece of research.

Following the terms of the person specification, essential consumer member attributes include experience of cancer (either as a patient or carer), 'a willingness to familiarise with medical and research language' and 'knowledge of consumer perspectives' (LRP annual report, 2008; 32). From this, one can assume an orientation towards life-world experience within the group, framed within a dominant medical sphere that necessitates lay engagement with systems talk.

An agenda, composed by the LRP secretary in collaboration with the Chair, is set and followed for each meeting. However, unlike the CSGs, there appears to be greater flexibility within the meetings, with more emphasis given to developing debate. As outlined in chapter four, the quarterly meetings last around four hours. During the first two hours members provide updates to each other about different projects that they have been involved in, researchers attend the meetings to present progress updates on projects which LRP members have been involved with, or researchers present new project ideas for LRP discussion and debate. During the last two hours of the meeting the LRP members discuss their own ideas for research projects. In particular, during the data collection period a small group of the LRP consumer members were developing a bid for a consumer led piece of research. During the last half of the meeting, the training sessions were sometimes held by the academic researcher working with the panel, or by the Chair. These included; literature searching skills, critical appraisal skills, qualitative research methods and analysis, quantitative research and survey based research methods, basic statistics and an introduction to health economics.

6.4.1. LRP: A group fulfilling multiple functions

Whilst the LRP was primarily established as a group of cancer carers and patients to assist researchers and influence and improve cancer research, it was apparent that membership of the LRP served multiple functions. These included social and support functions, self-help and advocacy functions, providing the opportunity for developing skills and in some cases establishing new careers, as well as the primary function of working with researchers in research. During an interview with the LRP secretary, Jean (who had worked for the panel since its initiation), supported my own observations:

"Well it [the LRP] has all sorts of functions. It has all sorts of social and personal functions for people on our panel. If you look at our panel it's extremely diverse. So for some people it's just a support mechanism, for some people it's an area where they can give back some kind of energy and get involved in something after they've had their treatment, and they find there's no where else where they can actually get involved. Because of their illness they're not able to resume employment or the groups that they feel they want to become part of, they feel they're a bit outside of. So it's got that" (Jean, LRP secretary).

In the above extract, Jean clearly points to the role of the LRP in filling aspects of consumer members' lives, such as providing an alternative to full time employment for some members, or offering support and social networks for other members. The multiple functions of the panel will now be explored.

First and foremost the LRP functions as a consumer research panel. There is an emphasis on the co-production of knowledge, with patients and carers working with professionals in order to improve the acceptability, comprehensibility and outcomes of research. For example, LRP consumer members were involved in research in a variety of ways. Robert (carer, Chair of LRP and CSG member) was active at both a local level as part of the LRP and also on various national groups, including a CSG and as a lay member of NICE guideline working groups. Likewise, a small number of the other LRP consumer members were involved at a national level, with one LRP member also involved as the Chair of the Human Tissue Authority and a couple of the LRP members involved as lay reviewers for the National Institute for Health Research, Research for Patient Benefit programme. At a local level, one LRP member was also a non-executive director of a Teaching Hospital Foundation Trust, whilst another member was a lay member of the local Clinical Trials Executive.

Throughout the year-long data collection period, there were a number of examples of local research projects that were brought to the panel meetings for consumer contribution. These included: advising on the acceptability and ethics of a research proposal; commenting on the wording and contents of questionnaires; and commenting on researchers' papers and poster presentations. In these cases, there was an indication of a shift towards the inclusion of life-world considerations into local research projects. For example, Louise (professional participant, LRP), who had worked with

consumer members of the LRP on a number of occasions, explained the various ways that consumer members had been involved:

"...they were an amazing resource and they helped us design our patient information leaflets, our patient approach letters, they helped us design our interview schedules. They helped us design so much and they've also written with us as well. Er, and they were involved in part of our data analysis and looking at interviews and doing original thematic analysis, or the early thematic analysis" (Louise, professional participant, LRP).

However, despite being involved in a number of different projects, it was apparent that the group wished to become more embedded at an earlier level into the local research network. As part of this, the Chair often expressed frustration that the requests for input that they received from researchers were often at a late stage in the project's development. This is illustrated in the extract below, when the Chair of the LRP, Robert, shared his frustration at researchers approaching consumer involvement in research in a tokenistic manner:

"I mean another problem is that the existence of the panel relies on professionals coming forward with suitable projects for us to get involved in. And to some extent that's a random process and it means that some researchers involve consumers as quickly as possible in their research projects. There are other members of the research community in and around the area that never even think about involving a consumer until the box comes up on the application form where they've got to involve. And sometimes we get very late requests for involvement which are a little bit disappointing and sometimes it's quite difficult to cope with. Literally they want somebody to read it and say yeah that's a good idea. Rather than see the early drafts or listen to the early ideas for the research and really get involved from the very beginning" (Robert, carer, LRP Chair).

Robert's concerns regarding the potential for the LRP to be involved in research on a tokenistic basis appeared to be shared by some of the other group members. For example, at a panel meeting in March 2008 I observed a group discussion about how they should 'promote' the work of the LRP to the local research community:

"There is a discussion amongst the group about how to increase the amount of requests for input into research that the group receives. A couple of the members express their disappointment that many of the requests for input that the group receives are quite superficial, with very few requests for early involvement in research. The academic facilitator says that they have to find a balance between letting the

research community know that the group would like to be involved earlier and trying not to put researchers off from doing involvement in the first place. Robert (carer, Chair) supported this concern and said that panel members needed to be wary about what light the panel should be shown in, stating that he didn't want them to be known as whiners and moaners. Sheila (patient) says that this can be difficult when they are frustrated about the impact that they have in research. She tells the group about her current frustrations with a research group that she is working with saying 'They've always made me feel very welcome, but there is a difference between being welcome and actually playing a role'. Robert acknowledges Sheila's frustrations but says the group need to work at changing researchers' attitudes by educating them and working with them rather than against them" (Notes from LRP observation diary, March 2008).

The extract above clearly highlights not only the concerns amongst the group regarding both the impact and role that they had in research, but also their concerns about how the group were perceived by the academic community. It was apparent that, in wanting to expand their involvement in research the group were keen to be regarded as accommodating rather than uncooperative, or challenging. Indeed, as Sheila (patient, LRP) suggested:

"I think your whole approach to it needs to be one of 'I'm here as a friendly, not as an enemy!' Because that's really important".

Consequently, the importance of working within the existing research structure was clear. However, as briefly discussed in chapter five, over and above the research function of the group, it would seem that for many of the group members, the LRP provides an important social function with the development of long-term friendships and an informal support structure that seemed to underpin and sustain panel membership. For example, Jean (secretary, LRP) would contact members over the telephone on a regular basis in between the quarterly meetings, to check on their health and wellbeing, particularly if a member was undergoing treatment or was generally unwell. For example, in July 2008 I noted the group response to one member suffering a relapse of their cancer:

"[Name removed] has relapsed. Jean was very quick to email around the group and arrange plans for people to visit. There is a general sense of rallying round, especially because [name removed] has no immediate family. The group members communicate via the group email to decide which members will visit [name removed] when and who will do certain household chores for her" (Notes from LRP observation diary, July 2008).

In addition to the support mechanism that the panel offers members, in line with the concept of the 'life-world', the LRP could be identified as a cultural site where shared understanding occurred amongst consumer members, and between consumers and professionals. Consequently, it appeared that panel membership afforded opportunities for sharing experiences of illness, treatment and care with other patients/carers and professionals. Furthermore, it appeared that the group provided a self-help/advocacy function. For example, during coffee and lunch breaks members could be overheard discussing their treatment, services and general health and well-being and as such sharing and providing support and advice. I frequently observed this type of 'talk' during the main meetings, with members updating the group on their health and recent experiences with services. For example, during a meeting in July I noted how a discussion about potential research topics that the panel members could build into a consumer led piece of research, turned into a session where members shared their illness stories:

"After lunch, 10 of the group members remained for the research subgroup part of the meeting. There was one new LRP member present, so Robert explained to them that the purpose of the research subgroup was a chance for members to discuss ideas that they might work into research bids for consumer led research grants. In particular they were interested in securing some funds from a large cancer charity that was providing financial support to consumer led research projects. Robert asks members to suggest areas that they have an interest in. This starts off quite productively, with one member suggesting that she'd like to look at the connections between reflexology and psychological wellbeing in cancer patients. The group discuss this idea and the member in question agrees to do a review of the literature with the help of the academic facilitator to find out what is already known in the area. Another group member suggests that they'd like to look into the provision of information for cancer patients. This topic seems to spark some interest and a number of different members start to tell their individual stories about the quality of information that they had/or had not been given during their treatment. This goes on for about half an hour and begins to feel like a support/self-help group, as members compare stories and offer advice to each other on the different treatments that they have received. After some time, the academic facilitator attempts to refocus the group by asking what they would like a research project in this area to focus on and recommends that they list some specific questions for the next meeting..." (Notes from LRP observation diary, July, 2008).

The extract above highlights the centrality of the 'life-world' within the LRP meetings. Even though the group has a research focus, it appeared to be

almost inevitable that at each meeting the group members would provide some form of advocacy/self-help function for each other. This may reflect the majority consumer membership within the LRP, as compared to the CSGs. The shared illness identity, or 'biosocial link' (Rabinow, 2002), between the group members is apparent and when confronted with a number of other people who have had similar experiences of ill health, treatment and care, consumer members appeared to appreciate the opportunity to share their stories. Moreover, in observing the way that the LRP moves between research, social and support functions, it would appear that in relation to consumer involvement in research, the boundaries between these different functions are far from clear.

Yet, whilst it was apparent from the observational data that the self-help/advocacy function plays a fundamental part of the LRP's existence, it is a function that the Chair appeared to be uneasy with as he frequently told me that the LRP was '*not a support group*'. Consequently, there were some emerging restrictions on the development of communicative action within the group. This issue will now be explored.

6.4.2. Discourse management in the LRP

Despite the apparent self-help function of the group, it appeared that there was an active process of discourse management within the meetings. In this way, the Chair and a minority of LRP members (in general it seemed to be those members who were also involved at a national level) appeared to monitor the group talk for what was considered to be a productive contribution towards the group discussion versus talk that was regarded as misplaced. When a member was perceived to be drawing too heavily on their own story or personal experience of illness/care, there appeared to be a number of techniques used to move the discussion forward. For example, overt attempts by the Chair (and the minority of members) to hurry some members along by reminding them that time was limited, or stating that particular issues could be discussed at a later time. This behaviour appeared to be particularly directed towards one member, Frank (patient). Often when Frank was speaking, I observed potentially covert mechanisms for devaluing Frank's contribution, such as smiling and eye rolling. During an informal chat with one of the professional members of the group, he expressed concerns

that the group 'tired of Frank very easily'. This could highlight one potential complexity of public involvement policy, whereby the acceptability of a lay member's contribution to a research meeting/group is based on imparting the *right amount* of personal experience. In this case, the appropriate amount of life-world experience appeared to be controlled by the Chair and a few of the other group members. Therefore, whilst membership of the group seemed to serve a social function for many members, the extent to which this could be drawn on at specific times was confined within the boundaries of acceptable talk controlled by the Chair.

At other times, other LRP members openly blocked the attempts made by some consumer members towards developing the self-help, support and advocacy potential within the boundaries of group remit. For example, during my observation of a group meeting in October 2008, there was a verbal disagreement between the Chair and some of the group members concerning what was considered to be acceptable 'group talk':

"During the 'any other business' section of the meeting, Robert tells the group that he is not happy that members use the group email to post items not directly related to research. This appears to be directed at a couple of members who have been sending information to the other LRP members regarding new treatments and complementary therapies. A couple of the members react very strongly against Robert's direction saying that they feel certain issues are worthy of group discussion regardless of whether they are specifically related to research. This sparks a debate around the table with members chipping in their opinions. The general consensus seems to be that members feel they would like to have some sort of discussion forum established where they can discuss issues related to cancer wellbeing and treatment. However, Robert takes a strong stance against this saying the LRP is a research group and that if members want to engage in general discussion about other issues they need to create their own discussion group. Robert's suggestion is rapidly met by one member who starts passing round a piece of paper to gather interested members telephone numbers and emails and they announce that they will start a discussion forum" (Notes from LRP observation diary, October 2008).

The extract above illustrates how the members in question wanted to debate the potential benefits of complementary therapies, diet and exercise in relation to cancer remission. Therefore, it would seem that some members were keen to develop the self-help focus of the group and the emphasis on communicative rationality. However, the Chair took a clear stance against

this exclaiming that the group existed in a professional capacity for the purposes of assisting, undertaking and influencing cancer research, stating that their discussion fell outside of the group's remit and moving the meeting on by introducing a subsequent agenda item. In this way, the Chair appeared to control the discourse and maintain a 'systems' focus within the group.

There were other occasions when the clash between system and life-world goals was observed within the LRP. During a meeting in the spring of 2008, the group engaged in a lively debate concerning how much personal experience consumers should bring to research meetings and how much constituted having one's 'own agenda'. On this occasion, the members seemed to be unable to reach a consensus concerning when and how they could discuss their own experiences of illness and care during research meetings, leading to some discontent about their actual contribution to research. Furthermore, the discussion turned to what actually constituted a 'consumer' in research:

"There is some discussion around the table about the term consumer and what it means. One member voiced an objection to consumer representatives who have a professional background and then get cancer and become consumer representatives, feeling that they don't have the essential consumer qualities because of their professional background. However, all of the other members appear to disagree with this opinion. It was then acknowledged that what the 'professional consumer' brought to research was different to other consumers but still useful. But, this suggestion was countered by the member who argued that the group could become overrun with 'professional consumers'. Another member felt very strongly that consumers shouldn't be limited by their lack of technical knowledge, stating 'It's more about how you give them that knowledge and confidence'..."(Notes from observation of LRP March, 2008).

Within the extract above, consumer members' concerns about the ambiguity of their role and where they 'fit' in research are clear. I often sensed that there was a constant state of flux between system and life-world aims within the LRP. Sometimes this amounted to visible tensions and frustration displayed by a small number of group members as they attempted to position themselves within this increasingly grey area concerning how much personal experience one can bring to the group. On a number of occasions this tension was observed as being particularly evident. For example, throughout the data collection period it became apparent that some group members were extremely keen to undertake various training courses in

research methodologies and cancer etiology. When discussing the purpose and perceived value of technical training, Moira (patient, LRP) was particularly concerned that she had not attended any and believed that training would help to build her confidence as an LRP member involved in research activities:

"I would feel a little better in myself. I don't feel confident" (Moira, patient LRP).

This often left other members, who had not attended the optional training courses, questioning their own contribution towards the group, with one group member, a carer, stating that she felt she had *"nothing to offer"*.

On another occasion during a group discussion concerning the potential of organising further research training for the group, one member, a patient, took a firm stance against this stating *"We are all here as people in our own right. Not to be experts in statistics and research"*. Furthermore, during discussions about the training needs of the panel, one of the academic facilitators for the panel was often heard repeating that members were not there to act as *'mini researchers'*, emphasising the importance of their experience as patients and carers rather than acquiring research skills.

Therefore, the tension between the ways in which individual members positioned themselves within the group was clear. Despite the LRP comprising a majority patient and carer membership, system/life-world integration was far from straightforward. These findings contribute towards an emerging discourse that appears to frame public involvement in research as inherently ambiguous. Consumer members appear to display uncertainty over what constitutes an appropriate contribution to health research. These findings suggest that the policy claims concerning the consumer role in providing a *'different perspective'* from the professional members may be fraught with complexity. As such these issues are given greater consideration in chapter seven.

6.5. Summary of chapter

The current chapter has explored the role of the consumer voice, or the life-world, within the NCRN. Specifically, examples of consumer/professional

interaction within the CSGs and the LRP have been explored and instances when the consumer voice has been integrated or blocked within these case studies have been highlighted. Whilst chapter five indicated that consumer motivations for involvement can be located within life-world claims, this chapter has indicated that the integration of these claims into research settings is a complex and multifaceted task. Far from providing a space for developing communicative rationality between consumers and professionals, some consumer members appear to have a restricted role in research, often relying on their physical presence to provide a 'reminder' to the professionals of the social and moral consequences of research.

The findings have highlighted stark differences within the CSG case study groups regarding the involvement of consumer members, the opportunities that are afforded towards a discursive agenda and consequently the role of the life-world within a systems orientated organisation. Emerging factors include the position taken by the Chair (supportive, dismissive or ambivalent), the cohesiveness of the group (in this study it often appeared to be dictated by the type of cancer and the group size) and the legitimacy of the consumer members' voice, e.g. if they are encouraged to speak by the professional members and if their questions are given consideration. Interestingly, even within the LRP there are apparent tensions between system and life-world aims, and the positioning of members within the group, the research community and the patient population.

As a result, it is apparent that the consumers' role in research is far from clear. From the findings presented in this chapter the policy claim that the involved public bring a 'different perspective' to research and furthermore that public involvement in research can be regarded as a form of deliberative democracy, whereby esoteric spaces are opened up to new questions and perspectives, appears to be questionable.

The findings in this chapter raise important questions concerning the position of the consumer in research and moreover the legitimacy of the consumer voice, or the life-world, in research decision-making spaces. In the next chapter, these questions will be explored. Building on the findings from this chapter concerning ambiguity of the consumer role in research and the apparent tensions in fulfilling systems and life-world aims in research spaces,

chapter seven will present findings concerning emerging constructions of consumer credibility in research.

Chapter Seven

Constructing the credible expert

7.1. Introduction

In the previous chapter, I presented the empirical research findings that reflected on the *practice* of consumer involvement in the NCRN Clinical Studies Groups and the local research panel. The chapter illustrated occasions when consumer members' experiential knowledge was voiced, integrated, or blocked within the case study groups. Whilst communicative rationality appeared to be evident on some occasions, it was also clear that systems rationality frequently governed the discourse within the case study groups.

Consequently, chapter six demonstrated how the integration of consumer members' life-world perspectives was far from straightforward. These findings prompt questions regarding the role and contribution of consumer members in research settings within the NCRN. Such questions are of particular significance given the epistemic claims made in the government policy, specifically those made by INVOLVE, and the sociological literature regarding the role of the public in bringing a 'different perspective' to research. Furthermore, the findings from chapter six raise important issues concerning the legitimacy of the consumer voice in research and the potential for experiential based knowledge to contribute to research.

In this chapter, I will explore further empirical findings that contribute to these emerging arguments. Drawing primarily on the interview data, this chapter will specifically cover the following areas:

- Professional and consumer epistemological rationalisations for public involvement in research and the privileging of certified forms of expertise.
- Training as a form of system/life-world antagonism.
- Issues of representativeness

It is intended that the findings presented in this chapter demonstrate that whilst initial epistemological rationalisations for consumer involvement in research, presented by many of the consumer and professional participants are suggestive of the 'experiential knowledge' claim that is often cited in the literature, consumer claims to credibility in research are more complex and diverse. Consumer credibility claims are fluid, seemingly founded on skills and attributes, above and beyond experience, that were suggested by consumer and professional participants as necessary for consumer involvement in research. As a result it will be argued that the unique contribution of the consumer voice, as distinct from that of the professional voice, is open to question.

7.2. Epistemological rationalisations for involvement

In the light of health policy claims concerning the distinct contribution that consumers are argued to bring to research decision-making settings (Hanley et al, 2004), this research explored how participants' rationalised consumer involvement. In order to explore this, consumer participants' were asked about the contribution that they felt they made to research, whilst professional participants were asked to specify the contribution they felt consumer members brought to research. Furthermore, participants were asked to reflect on any specific skills or attributes they perceived to be necessary in order for consumer members to contribute to research decision-making settings. Within the consumer and professional interview accounts varying epistemological justifications for consumer involvement in research emerged.

Drawing on Dyer's (2004) framework for lay involvement in Local Research Ethics Committees¹, Collins and Evans (2002) concepts of 'interactional' and 'referred' expertise², and the wider literature concerning the emergence of lay knowledge and expertise (as explored in the literature review), the epistemic rationalisations, as constructed by the participants, will now be explored.

¹ Dyer (2004) suggests two models of participation: The 'extra scientific model' and the 'scientifically engaged model'. Both of these models are explored in the literature review.

² Collin's and Evans (2002) normative theory of expertise suggests three types of contribution to technical decision-making: Contributory, referred and interactional. These are outlined in the literature review.

7.2.1. Experiential knowledge

Within the consumer interview accounts almost all of the participants' made initial claims to the importance of their personal experiences of illness/caring, and/or healthcare services and treatment with regards to their contribution to research. For example, when asked about what she brought to research decision-making, Clare (patient, CSG subgroup) stated, "*My credibility is my experience of [cancer type removed] cancer specifically*". Clare is clearly claiming credibility in research based on her subjective experience. Similarly, when asked the same question, Alan (patient, CSG3) pointed to the *first hand experience* of patients and carers:

"Well the first point is firsthand experience of the disease area. That is essentially what you're bringing into that debate. Now firsthand experience may be as a patient may be as a carer, you know we have a number of instances of partners who've lost a husband or a wife, or in one case we have a guy who lost both his parents to a disease. So that firsthand experience is critical. It's a spectrum of people and individual experiences within that one core principle" (Alan, patient, CSG3).

Such accounts seemingly suggest an epistemic claim based on experiential knowledge of cancer. Furthermore, Alan's account, as provided above, begins to identify a plurality within the 'patient voice' by referring to a *spectrum of people*. Drawing on their experience, consumer participants also talked about the 'different perspective' that they brought to the research process. In this way, the consumer contribution was framed as providing something distinct from that of the professional researchers. Jenny's (carer, LRP) quotation is illustrative of this point:

"You get a different viewpoint, totally different and I think it really brings reality to bare sometimes because I think clinicians, researchers go off on the task... and I think sometimes a real person brings, can hone in on something that they'd probably not seen or ... I just think it rounds it a little bit better, hopefully anyway" (Jenny, carer, LRP).

Jenny's construction of the consumer contribution to research suggests the consumer as providing a sense of 'reality check' and what Jenny appears to regard as a necessary reminder to the clinicians and researchers of the human face of research, the *real person*. Such a construction would imply that clinicians and researchers can forget about the human implications of research and that the consumer members' role is to provide such a reminder.

This corresponds with Jasanoff's (2003) analysis concerning the place of lay participation in expert decision-making settings. Jasanoff (2003; 398) suggests that:

"...expertise is constituted within institutions, and powerful institutions can perpetuate unjust and unfounded ways of looking at the world unless they are continually put before the gaze of laypersons who will declare when the emperor has no clothes".

Whilst Jenny never elaborated on the exact nature of the 'different viewpoint', and indeed what sets such a contribution apart from that of the professional members, in appealing to the consumer role in 'rounding' research, such a construction may be suggestive of a 're-coupling' of system and life-world perspectives. The life-world, vis-à-vis the consumer voice, is brought back into the system. Above all, it would seem that Jenny's construction of consumer credibility in research is based around values and, as such, appears to be compatible with Dyer's (2004) extra scientific model for involvement.

Using the experiential expertise justification for involvement, other participants talked about contributing their perspective regarding the running and process of specific research projects. For instance, some participants spoke of their role in advising on the recruitment of research participants and developing information sheets for potential research participants. In this sense, it appeared that participants' felt that they could provide a unique perspective within deliberative research forums, based on their ability to provide an evaluative function by drawing on their own experiences and accordingly providing a value assessment:

"You know how you were treated. I have no complaint about my treatment at all. I had wonderful treatment, it wasn't nice but I can't fault how I was looked after and how I was dealt with. But because I had the experience personally of that, when they now start to talk about what they want to do with the patients in this group, I think 'would I have been able to have coped with that or would I have liked it done differently'. So I draw on my own experience which obviously nobody else can do" (Sheila, patient, LRP).

Similarly, Fiona (patient, LRP & CSG) spoke of consumer involvement in research as contributing 'a worldliness':

"I think we bring a worldliness that is different from pure academics' point of view. I think we can sometimes ask and answer questions

that they don't know how to deal with. As a slight example of that I think sometimes professionals feel that they must treat continuously and that people want the maximum that they can. So they will keep doing it even though they know you're going to die and some of the implications are that the treatments will make you very very ill. And that whole debate is about when do you stop? And does that then create hopelessness in that person and then gives up 'they've told me there's no hope, it's kind of curtains here'. And I think sometimes as a patient you can say 'well this is my experience and this is how I would take it' and you can perhaps sometimes just give experiences about what it feels like" (Fiona, patient, LRP & CSG).

Consequently, validity was given to subjective knowledge and individual experiences appeared to be recognised. 'The patient voice' encapsulates a whole range of experiences, attitudes and perceptions, based on the core commonality of patienthood – and in the case of this research, in relation to experiences of cancer.

Arguably, consumer rationalisations for involvement, based on experience can be located within the exploration of experiential knowledge suggested in the sociological literature by Caron-Flinterman et al (2005a), Popay and Williams (1996) and Stevenson and Scambler (2005) amongst others. As found within the wider sociological debates, consumer members' experiential claims appear to be based on their implicit, 'situated knowledge' – knowledge developed specifically through experiencing phenomena firsthand. Consumer members' accounts, with their emphasis on subjective experience, can also be located within Habermas' (1987) construction of the 'life-world' – where cultural and social meaning is reproduced.

Building on this, Ruth (patient, CSG) described the unique contribution of the consumer member based on their position 'outside of the system':

"Well I think it's, it is different being a patient. I mean erm, because you're not really part of their system, you're part of the big system but it's like a secret mafia really, they've all got their agendas and their roles and their hierarchies and coming from all over the country and you get the feeling there's competition between different hospitals. So you're representing yourself as a patient but also other people who've got [cancer] who are all over the country so quite a big responsibility really".

Again such an account of the consumer contribution to research appears to be founded within the realm of values, with consumer members providing the types of 'moral and social filters' as suggested by Dyer (2004) in the

extra scientific model of involvement. Yet, as with Jenny's account, Ruth's construction of the consumer perspective and contribution appears to lack any specificity.

7.2.2. Professional appeals to experience

Within the professional accounts for consumer involvement, epistemological rationalisations based on the experiential knowledge of the consumer members, were the most prevalent. In particular, these rationalisations appeared to correspond with Dyer's (2004) extra scientific model for involvement. For example, Peter (Chair, CSG3) described the consumer members as bringing 'common sense' to the research group:

"Well part of it is common sense, if we're talking rubbish, some of them are very clear to say 'hang on you guys, you're asking the wrong question' and that's been very helpful" (Peter, Chair, CSG3).

Peter's account of the consumer role in challenging the expertise of the professional group is indicative of the 'emperor has no clothes' contribution that Jasanoff (2003) suggests and the constructions suggested by consumer members themselves (as discussed in the previous section). Furthermore, observations of CSG3 supported Peter's construction of an active consumer role and chapter six reflected on the degree of consumer/professional interaction within this particular case study group.

As part of the experiential knowledge claim, occasionally there was a sense that some of the professional participants were attempting to construct boundaries between the consumer contribution and the professional contribution to research. For example, the consumer member was sometimes framed as the 'uninitiated' within the domain of technical expertise. Such a construction was often suggested in a positive light, with consumers' perceived naivety of technical issues equipping them to question the 'taken for granted':

"I mean, I think, I'm sure a lot of the time they're probably frustrated and thinking that they don't feel involved. But I think if they weren't there that would be a huge detriment and to some extent it does depend on the individual themselves as to whether they contribute or not. But when they do, their, you know it's often when we're discussing something and they say 'hang on why are you doing that?' and it does make us stop and think about what we're doing. So it's a

useful jog and a reminder about what this is all about – improving things for the patient” (Joanne, professional participant, CSG4).

Again, as with Peter’s construction of consumers as the contributors of ‘common sense’, Joanne’s rationalisation is suggestive of consumer credibility in their questioning of scientific decisions. Above all else, from these accounts it would appear that consumer members’ value within research groups is reliant on their provision of a fresh or ‘uninitiated’ perspective. As with the consumer constructions of the ‘different viewpoint’, these accounts are suggestive of the consumer role in providing value judgements, or an evaluative function, based on their subjective experience of illness, caring or treatment, or their experiential knowledge.

Only one professional participant explicitly rationalised the consumer contribution in terms of their ‘experiential expertise’. This can be seen in the account provided by Louise (professional participant, LRP) below:

“So as a group, you know in our meeting it was always very interesting, everyone had their own say, opinions were respected and so I think if you recognise you’re not asking consumers to be researchers you’re asking for their expertise as people who have used the service or have a specific need. And that is their expertise therefore, and if you respect that then they respect you are a surgeon or a qualitative researcher, nobody’s replacing anyone’s role” (Louise, professional participant, LRP).

What is interesting in Louise’s account is that in providing a role for the consumer members based on their ‘experiential expertise’, it appears that the boundaries of the professional role are also strengthened. Restricting the consumer contribution to their experience, according to Louise, ensures that ‘nobody’s replacing anyone’s role’. Essentially in associating experience with expertise it would seem that a greater degree of credibility is given to the consumer role in providing personal, subjective and tacit accounts. Accordingly, the professional role in providing certified forms of knowledge should be equally respected by the consumer member. This could imply a sense of ‘knowing one’s place’ - essentially preventing consumer members stepping over the mark and commenting on areas considered to be outside of their designated area of expertise.

A further function of the experiential rationale for involvement identified by the professional participants appeared to be in providing an ethical or moral filter on research. As part of this, the consumer role was based on their

ability to relate research ideas to their own experience and reflect on the acceptability of research protocols in light of this – e.g. placing themselves in the shoes of potential research participants:

"Well if they've contributed to a discussion as part of the team, they often remind us of things that we've forgotten. Or with a randomisation they might say what they see as acceptable because sometimes it's often the clinical researchers who think that the patient wouldn't find [things] acceptable and it's our patients who say 'well actually that's fine, I would find it an acceptable trade off for this amount of expected benefit'. So they're the ones who have been in that position. So their input is valuable" (Joanne, professional participant, CSG4).

Joanne's suggestion was supported by Karen (professional, CSG3) who suggested that the consumers' role was to assess the feasibility of research, i.e. *"if it's possible for the patients to attend so many times..."*. Again, these accounts are suggestive of the extra scientific model of involvement, with consumers bringing the 'social context' (Dyer, 2004) to science.

However, as discussed in chapter six, the opportunity for consumer members to provide such a contribution to the research groups was variable. In providing a 'common sense' perspective, or a 'different viewpoint' one may query the weight that such perspectives would carry against the certified expertise of the professional members. For example, one may conceive of such constructions as part of a facts/values spectrum, with certified, professional knowledge located within the realm of 'facts' at one end of the spectrum and the 'different viewpoint', or experiential knowledge located within the realm of values at the other end of the spectrum.

As discussed above, some of the professional participants spoke of the 'uninitiated' consumer member in positive terms, as it appeared to provide a sense of distinction between the 'facts' and 'values' roles of professional and consumer members and placed the consumer role within the extra scientific model of involvement. Yet, not all of the professional participants regarded consumers' experiential knowledge as sufficient for a role in research. For example, some professionals seemed to appeal to a paternalistic construction of the consumer, placing limits on their abilities to be involved in research. In the extract below, Shona (professional participant, CSG5) suggests this:

"But clearly when we're designing a study you're looking a lot, you've got your power to establish and statistic and to have a patient sitting

there, looking a bit confused is not fair on them. There's not many patients who understand the power of the study and how many patients and how many research questions you can ask given this number. And I think it's a little bit much to expect a patient to come on. I mean they've said to me at the lunch break of these meetings, the ones that have turned up, 'I'm completely bewildered by all this'. So it isn't just my impression, they've told me" (Shona, professional, participant, CSG5).

In Shona's account, credibility is placed in professional, certified expertise and knowledge of 'statistics' and 'power calculations'. Consumers' lack of knowledge in these areas is framed as detrimental and accordingly their credibility and role in research open to question.

Building on this, two of the professional members of the CSGs were extremely forthright in their rejection of consumer membership of the groups. For these two members, consumer involvement in the CSGs was ultimately perceived as inappropriate. To illustrate this, the interview extract provided below, shows the development of one professional participant's (James, professional participant, CSG1) argument. James' argument suggests that scientific and academic research should be bound within the confines of the certified expert role and should not be open to the incorporation of experiential knowledge.

Interviewer: *And how useful do you think that role (the consumer role) is?*

James: *Are these comments going to be attributable or not?*

Interviewer: *No everything is anonymous.*

James: *Well personally I think they are of limited value. It's politically correct to have them on board. But if you really want my honest, I wouldn't quite go so far as to say they are a waste of time, but I think they are of relatively limited benefit.*

... ..

Interviewer: *... a few people have told me that they think the subgroups are a more appropriate place for them to have input...*

James: *No I would totally disagree. I would say that the sub groups are working groups that should be composed of the experts and that's why you have the lay person on the full committee. I would say to have a lay person on the subgroup I think would be negative, would I think interfere with the function of the subgroup. If we have them then they should be on the full group and that's where they can make their comments and have their voice heard. But to have them on the subgroups I think would be disastrous"* (James, professional, CSG1).

James' attitude towards the consumer role is relatively clear, perceiving consumers to be of *limited value* and their membership of the CSGs as '*politically correct*'. Furthermore, experiential knowledge is regarded as inferior to that of professional knowledge with the potential that consumers may '*interfere*' with the systems orientation of the research groups. Above all, it would seem that experiential knowledge has little credence in a group orientated towards specific systems outputs.

Similarly, in associating the consumer voice as an inferior way of knowing and questioning consumers' credibility within research decision-making groups, consumer knowledge was sometimes readily dismissed in favour of professional expertise. The example below, provided by Anne (patient, CSG1), highlights this. Anne's account demonstrates the potential for traditional patient/professional roles to be emphasised within research decision-making groups, ultimately reducing the credibility of the patient/carer voice:

"I was introducing myself, I obviously had to say why I was there, which meant saying about the cancer and what cancer I had. And I described it in the terms in which it has always been described to me.... And when I'd finished my little spiel, one of the guys opposite me, a very snooty one, said to me 'just for your reference we don't call it that anymore we call it a ...' and then he gave me the medical term. In a really put down way" (Anne, patient, CSG1).

Far from encouraging a *plurality of expertise* in decision-making spaces, as some of the literature states (Pellizzoni, 2001; Scambler & Martin, 2001), Anne was left feeling, in her words, '*utterly deskilled*'. Her own sense of legitimacy from her patient status, or experiential expertise and her position within the group, was undermined. Rather than embodying an active and involved member of the group, the danger here is that paternalistic power relationships may be reinforced, resulting in increased passivity on the part of the consumer member.

Therefore, the findings suggest initial rationalisations for involvement in research (suggested by consumers and professionals), largely based on consumers' experiential knowledge, or their '*different viewpoint*'. These constructions have resonance with Dyer's (2004) extra scientific model with the consumer role in research as providing the '*social context*', or arguably

the 'life-world' perspective. The exact nature of such contributions appears to be difficult to ascertain, and indeed as illustrated in chapter six such contributions can be readily dismissed or blocked. Yet, arguably these rationalisations are closely related to the policy claims made by INVOLVE regarding the 'different perspective' that the public can contribute to research.

However, as will be explored in the following sections, regardless of the initial credence given to the experiential justification for involvement, a number of other rationalisations for involvement began to emerge. In addition, it appeared that many consumer members (both CSG and LRP) were actively involved in redefining the boundaries of their epistemic claims to involvement beyond their experience, essentially re-conceptualising the way in which they position and identify themselves within the wider research community. These additional rationalisations for involvement will be explored in the subsequent sections. Prior to this, a further important aspect of credibility in research will first be discussed – consumer privileging of certified expertise.

7.2.3. Privileging of certified forms of knowledge

The findings from the interview and observational data suggest that one commonality between the majority of consumer members was an apparent privileging of professional, or 'certified', forms of expertise. Rather than conceding to an overt mistrust of science (as some contemporary sociological accounts claim³), the consumer members in this study appeared to not only support the dominant techno-scientific discourse, but also readily deferred to it in place of their own experiential knowledge. Moreover, it was apparent that many of the consumer members maintained relatively 'traditional' perspectives on expertise, in the sense that they often highlighted and reinforced the professional/consumer demarcation. For example, Sandra (patient, CSG2) stated:

"I would always respect somebody's profession and I work on the basis they know what they're doing and they care about what they're doing".

³ For example, accounts provided by Beck (1992) and Giddens (1991)

In the extract above, it would appear that Sandra places faith and trust in the professional members to maintain certain professional standards; ensuring that they work with integrity and passion. Similarly, Shirley (carer, CSG subgroup) accounted for her trust in the patient/professional relationship based on her age and the 'traditional' paternalistic model of healthcare being the dominant model during her life:

"They're professionals and I'm a carer. I mean it is a very very wide gap. I didn't know anything about explaining how individuals tick ... and because I'm old as well, I mean I'm 72 years old, now. In my young days, I mean I remember when my parents paid a shilling a week for the whole family to be looked after by a doctor. And the word doctor was god. And for a lot of older people, I mean this is coming through the system now it's changing. But for the older people and a lot of the [cancer type removed] cancer patients are in the older age group, 70s and 80s even, you know you didn't question the professional man".

Shirley's construction of paternalistic professional/patient relationships may account for the continued trust that the consumer members in this study seemingly placed in the professional role. Furthermore, it could also account for the common construction of consumers working collaboratively with professionals rather than challenging professional roles. For example, during observations of CSG3 and CSG4, two of the consumer members made explicit claims that they were there 'to help' the professional members. Such cooperation was also apparent within the LRP when consumer members were observed to frequently discuss how they could work within the existing organisation and structure. Implicit within these observations was the consumer preference for adapting and working with the system, or as Sheila (patient, LRP) put it, "*finding the lay of the land*". Sheila clearly illustrates this point in the quotation below:

"I think your whole approach to it needs to be one of 'I'm here as a friendly, not as an enemy'. Because that's really important. And I would suggest that for the first meeting unless you are specifically asked a question or asked if you have anything to say, you go and you get the lay of the land. You go, almost if you like, to observe and see how it functions ..."

Within Sheila's account the consumer member can be regarded as being subject to the existing 'rules of the game'. As a result, one may query the extent to which they are able to contribute their 'different perspective', or indeed provide a challenge to dominant certified expertise if they are conscious of remaining as a 'friendly' (albeit passive) collaborator.

Whilst consumer members' often referred to themselves as 'equal partners' – *"we're there on an equal basis"* (Alan, patient, CSG3) – playing a 'complementary role' (William, patient, CSG) to those of the professional members, it was apparent that this role was frequently framed within the boundaries of the expert/non expert divide. Indeed, the privileging of professional expertise extended so far as to prevent some consumer members from voicing experiential contributions for fear of making an unqualified claim. For instance, Shirley (carer, CSG subgroup) described how she was careful about what she said during the meetings as she *"did not want to put [her] foot in it"*. Furthermore, during my observation of the CSG subgroup, it appeared that Shirley repeatedly positioned herself in the role of the 'unknower'. Referring to herself as *'thick'*, or claiming that she *'always goes off on a tangent'*. From this, one can infer where Shirley identifies her credibility in research – perhaps not as an equal partner or co-collaborator, but rather as an invited guest, potentially reinforcing the consumer/professional, or non-expert/expert divide.

A further aspect of the preference given to certified forms of expertise was inferred from consumer members' keen interest in undertaking training and receiving certified accreditation. For example, Mary (patient, CSG) described the various training courses she had attended:

"Well the training is ongoing. It's an ongoing thing. I've had two or three sort of one day study days, I've had an introduction to cancer course in Birmingham which is a three day course. I've had a one week course at Oxford on clinical trials on how to, well it was about the statistics, on how to compose, how to conduct trials, how to go about it. But it was a lot about the statistics and things like that. The pitfalls that you could fall into and things like that and pitfalls that many people do fall into. So it was really interesting...both of those last two and particularly the introduction to cancer course was very good and they reminded you of things that you might have forgotten. You know what is it, various details about different types of cancer and about radiotherapy and so on. So yeah that was extremely good. It was aimed really at research nurses, so it was ideal for lay people as well. The one at Oxford was aimed at people already in research. There weren't many consumers, it was mostly medical types, you know, who wanted to do research. So it was possibly aimed a tad higher than that, but it was okay. I really enjoyed that" (Mary, patient, CSG).

The breadth of training, as described by Mary in the extract above, is indicative of the experiences of many of the consumer members. Mary's enthusiasm and passion to develop her understanding of the various certified

forms of knowledge is clear. The implications of this will be explored in section 7.2.6 (*Training as a form of system/life-world antagonism*).

In addition, a heightened sense of consumer credibility was found to be associated with professional certification, with Shirley (carer, CSG subgroup) proclaiming:

"If I didn't have some sort of academic qualification I wouldn't have enough confidence to take part".

Whilst Mary's (patient, CSG) argument is further illustrative of this point:

"The fact that you've got a few letters after your name yourself, you don't feel quite so bottom of the pile I suppose".

Consequently, it has been argued that participants' initial rationalisations for consumer involvement in research are situated in consumers' experiential knowledge. This justification for involvement initially locates the consumers' credibility in their subjective experience. However, as explored in chapter six, the integration of experiential knowledge was often far from straightforward. Additionally, it was also apparent that certified forms of knowing were held in high esteem by the consumer members, with some consumers regarding their contributions to research as less worthy than those made by the certified experts and there was an apparent eagerness amongst the consumer membership to undertake training in specific certified forms of expertise, such as statistics.

Accordingly, due to the apparent ambiguity further rationalisations for involvement in research were developed by the participants. These will now be considered.

7.2.4. Scientifically engaged?

Whilst experiential knowledge was advanced by participants as a central justification for consumer involvement in health research, further additional rationalisations were identified suggesting the limits of the experiential claim. As part of this, a justification based on the possession of prior knowledge and skills, considered to be relevant to research, was made. Thus, some participants explicitly drew on their previous career, education and training,

in addition to their experiential expertise. This was done in differing degrees in what appeared to be lay participant's active attempts to establish themselves as more or less credible members amongst both lay and professionally dominated groups. For example, Sheila reflected on how her previous clinical experience as a GP allowed her to see both the clinical and the patient perspectives expressed during research decision-making meetings, where she attended as a lay participant:

"So it's almost like I wear two hats and depending on where I am, half the time I might be with one hat, the other half of the meeting I can be with my other hat on. What I have to be really careful [about is] that because I understand my medical colleagues and the stresses and strains that they are under today...On the other hand I want the very best for my patient colleagues..." (Sheila, patient, LRP).

Sheila's construction of her dual role, and dual allegiance, appears to be similar to Kerr et al's (2007) construction of a 'hybrid position'. Kerr et al (2007) studied expert and lay claims to expertise within scientific events that were open to the public and where professional/public dialogue is encouraged. Kerr et al (2007) found that participants often adopted 'hybrid positions' - claiming both expert and lay knowledge positions. These hybrid positions appeared to provide participants with a unique claim to credibility, claiming commonality with other lay people through their possession of experiential expertise, whilst also establishing a degree of credibility amongst certified expert/professional positions by asserting their own certified expertise or qualifications. It certainly seems that Sheila was involved in a similar process. However, it appeared that this process was not clear-cut and Sheila described the difficulties that she faced in trying to maintain such a hybrid position:

"So there's a fine line and in some instances I do probably speak out of turn, against both hats and for both hats... So I see my remit as trying to keep the status quo between the two".

Drawing on her certified expertise from her medical career, Sheila appears to possess what Collins and Evans (2002) would label as 'referred expertise'. Though not directly related to the research areas, in which she is now involved as a consumer member, elements of Sheila's clinical training and knowledge can be applied within research decision-making groups.

Along with Sheila, a small number of the consumer members were medically qualified. This group of consumer participants seem to emerge as a distinct category within the wider consumer group; involved by virtue of their personal experience of illness or caring, yet in some ways feeling that they have a heightened legitimacy amongst the scientific and research community because of their professional training, or 'referred expertise'. At times this was verbalised as the sense of belonging that the 'hybrid position' allowed, as previously mentioned:

"Because they're my colleagues, or my old colleagues. So they saw me as one of them! As opposed to a patient" (Sheila, patient, LRP).

At other times, it was expressed as a feeling of confidence in consumer members' ability to integrate into the scientific world:

"...I think I felt as a clinical nurse specialist because I had that, sort of, nursing background it would be a bit easier for me than someone just off the street. And reading through what they wanted I thought 'well it's not going to be quite so daunting for me', because I had that, sort of, experience" (Ruth, patient, CSG).

As discussed in the previous section, some consumer members undertook various forms of training courses, ranging from basic cancer and research terminology and jargon busting courses, through to basic statistics, and qualitative and quantitative data analysis courses. By undertaking training, consumer members developed their abilities to interact in the dominant discourse.

Indeed, the language used by some consumer members is of particular interest here. It appears to highlight, not only the skill level that many consumer members were operating from, but also the way in which the dominant techno-scientific discourse, around clinical trial methodologies has been embraced. For example, within the interview transcripts there were clear examples of lay participants adopting clinical and research terms. One participant made reference to a 'double blind randomised control trial' as the 'gold standard' in research (Robert, carer), whilst another talked about the effectiveness of different 'care pathways' (Alan, patient). These provide interesting examples of the 'professional talk' that had been readily adopted by the lay participants. The development of this expertise is suggestive of Collins and Evans (2002) 'interactional expertise', whereby consumer members are able to interact with the dominant discourse, thus enhancing

their claim to credibility in research. Though perhaps not occurring to the same degree as evidenced in Epstein's (1996) study of the HIV/AIDS activist community, from the findings it would appear that within the cancer network there is certainly an indication of a growing body of mobilised and scientifically engaged patients and carers.

It could be argued that training and development of interactional expertise is a form of 'proto-professionalization' (De Swann, 1990 in Shaw 2002) whereby lay members of expert committees and groups adopt the terms and concepts of the expert group. This in turn blurs the boundaries between expert and non-expert. Indeed, as will be explored in section 7.2.6 (*Training as a form of system/life-world antagonism*) it appeared that the training offered to lay members involved in research added to the ambiguity and re-assessment concerning the consumer role and positionality within research decision-making spaces. Lay participants' eagerness to adopt the scientific discourse demonstrates how the techno/scientific is held in high esteem. It also indicates a general feeling that in order to play an effective role in research decision-making groups lay members must assume the dominant scientific discourse. This potentially undermines the language and discourse of the life-world. Moving away from the experiential claim to credibility, such 'referred' or 'interactional' expertise, as described in the above accounts, locates consumer credibility in research within their ability to engage in the techno-scientific discourse. Accordingly, the accounts appear to resemble Dyer's (2004) 'scientifically engaged model for involvement'. Again this appears to contradict the experiential expert model, which suggests a model of consumer involvement in research based on consumers' experience, instead advocating for more limited consumer involvement in research based on specific criteria, skills and knowledge.

It was also interesting that some consumer members had developed expertise (and reflexive critiques) of public involvement itself. During the interviews, some lay participants drew on a wealth of knowledge covering the historical, theoretical, political and cultural context involved in the academic debate in this area. Similarly, a small number of the consumer members, had developed in-depth knowledge of public involvement policy, how the public can have an impact and influence within cancer research, the research infrastructure, and the barriers and facilitators to public involvement. During an interview, one participant, Alan (patient), provided a

detailed account of the philosophical, ethical and moral 'textural layers' that public involvement encapsulates. Whilst another participant, Robert (carer, LRP & CSG) told me about how heavily involved he had become in his various lay advisory roles across the country and that he had increasingly come to be known as an 'expert' in the area:

"But literally, well we're all over the country talking about user involvement in cancer research. I did a list of the towns that I've visited recently yesterday, about 12 cities all the way from Newcastle in the North to Slough and Bristol in the south of England. So we're here there and everywhere and the list grows. Even yesterday an email wanted me to go to places that I never thought I could... I think for me, my role now is not so much for me to be involved in the research process, because I think I might have gone beyond that, I think my role now is to fly the flag for consumer involvement and convince the powers that be, up there, because I actually get to talk to some of these people now, to convince them that involvement at the local level is the way forward " (Robert, carer, LRP & CSG).

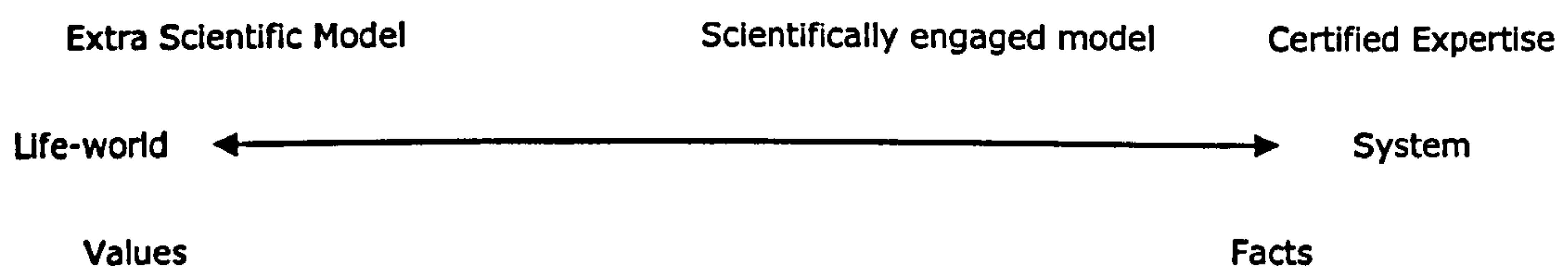
Taken together these accounts are also suggestive of Dyers (2004) 'scientifically engaged' model of participation, suggesting credibility based on consumer members' knowledge and understanding of the scientific literature and their ability to converse in this language. Furthermore, Robert's account highlights his concerns regarding consumer professionalization – a point at which a small number of consumer members and some of the professional participants queried when a consumer member may lose their grassroots credibility as they become more deeply ingrained in the professional discourse. This argument will be further explored in section 7.2.6.

What emerges is almost a hierarchy amongst lay participants. Using Dyer's (2004) models of participation, one can perceive those with the basic requirement of experiential knowledge at one end of the spectrum, whilst those who are more informed and integrated into the clinical systems, the 'scientifically engaged', are at the other end of the spectrum (See figure 7.1). At the 'scientifically engaged' end of the spectrum, some consumer members appear to have established themselves in the role of 'educator' for other lay participants, or as a communicator between the lay and expert worlds. By assuming such a role, they claim both lay and expert knowledge, and accordingly commonality and moreover credibility with both the patient/carer members and the professional members of research groups. Again this idea of an educator was apparent in Sheila's (patient, LRP) construction of her 'hybrid position':

"I go to the more medical orientated meetings with my medical hat on to gain the knowledge but come back and provide it so that the rest of the panel, who are non medical can understand what's going on and be a voice, make some sensible comments and then it's fed back into the system".

However, the two ends of the spectrum are not discrete, and many consumer members seemingly fall between the extremes, having undertaken some technical training. Furthermore, as consumers become more deeply involved in research and cancer research, many of them will invariably progress along the spectrum increasingly moving towards the scientifically engaged model of participation, suggesting a sense of fluidity across the spectrum.

Figure 7.1.



What this potentially indicates is that some participants are engaged in extending and developing the parameters of their real and potential contributions to the research world, with a contribution beyond experiential expertise. The following section builds on this theme by exploring the development of normative frameworks for involvement that were apparent within the consumer and professional rationalisations for consumer involvement in research.

7.2.5. Normative frameworks for involvement

As has been shown, the experiential knowledge rationale potentially legitimises the involvement of patients and carers in research based on their personal experience of a specific research area. However, what became evident from the findings is that many participants, particularly those within the consumer group, are engaged in the process of developing their own normative frameworks for involvement. The development of such frameworks moves beyond experiential knowledge as a basis for consumer

credibility in research and encompasses aspects that participants regarded as necessary skills and attributes for a justifiable role in research.

When asked about what qualities, if any, were necessary for lay members to be involved in research, a number of suggestions were put forward by participants. Key skills and attributes, including the ability to express oneself confidently and to be able to assert one's opinion in a clear and concise manner, were suggested by some participants. This indicates that there is a preferred mode of behaviour, one that fits with the existing institutional structures and discourses.

"So confidence is definitely important. You need to be able to speak, not necessarily very eloquently but you need to put brain into gear before opening mouth. You can't just sit and waffle. You need to have formulated in your mind before you speak what it is that you really want to say. Because they're not people who suffer fools gladly" (Sheila, patient, LRP).

Furthermore, good working relationships between consumers and professionals, were sometimes believed to result from involving the 'right consumer' (Louise, professional, LRP). Key attributes for successful collaboration identified by professional participants included 'intelligence' (Steven, professional CSG4) and previous experience of committees:

"...I think they need to be familiar with sitting on committees, or have a little bit of a medical background. And that doesn't mean they've got to be a paramedic, a nurse, a doctor, or something like that. Have a little bit of insight into the way things work" (Peter, Chair, CSG3).

There were also some interesting paradoxes and ambiguities evident within these emerging normative frameworks for involvement. For example, a few participants referred to the sense of naivety and freshness that is associated with being new to the health research area, coupled with the ability to maintain a certain distance from the 'system': These were cited as key qualities that lay members could bring to research. This would follow the extra scientific model of participation (Dyer, 2004), based on the role of the lay participant in questioning the 'taken for granted':

"Because it's a naivety which actually, the person who asks the questions and says, you know, and says 'the emperor has got no clothes on' type of thing which is most important" (William, patient, CSG).

However, a number of other participants spoke of the importance of having some knowledge of the wider clinical area that a particular condition may be linked with, as well as knowledge and skills in research methods in order for a member of the public to be a credible member of a research team. This is more in fitting with the 'scientifically engaged model' of participation, based on a participant's capability to communicate effectively within the dominant techno-scientific discourse (Dyer, 2004).

"...there has to be an ability to learn, to be committed to this efficiently. To learn about the disease area so that you don't just understand the disease that you or your loved one faced, that you understand all associated diseases to some extent" (Alan, patient, CSG).

There was also a sense that participants were actively conceptualising 'how much' knowledge was necessary in order to participate effectively in health research decision-making spaces. Too little knowledge, according to some participants, could be seen as a limitation and could restrict their potential input into the research process. On the other hand, too much knowledge could lead to lay members becoming 'professionalised'. 'Professionalization' was seen to occur when lay members became 'part of the system', taking on the dominant operating framework of the group, consequently failing to question the norms and values of a research group as they might have previously done. This can be seen in the following quote:

"Interviewer: ... you said all of you are quite experienced. Do you think that's been necessary?

William: I think that's probably very useful, I think that it's also useful to have these things if you possibly can because as I was saying before, if you're not careful you can become a professional service user. Because you know you've been there done that one. And if you're not careful you tend to think in the same kind of regimen as the actual professionals" (William, patient, CSG).

This was interesting in that some participants clearly felt that there was a contribution that they could bring to research that differentiated them from 'professionals', yet at the same time they were conceptualising a point at which one would potentially lose this contribution to research. Once this occurred, new conceptualisations of lay participants' roles emerged. Indeed, another participant, Robert, described himself as an 'activist' for public involvement:

"I do see myself as an activist and to some extent I think the freshness and the enthusiasm and naivety that I brought to the research process four years ago disappeared and to some extent I've become professionalised" (Robert, carer, LRP & CSG).

Further examples of the apparent antagonism between instrumental and communicative rationality were inferred from my observations. For instance, during my observations of one particular consumer meeting (where members of the LRP and the CSGs were present) there was some disagreement over the role and place of the 'professional consumer'. By this, I refer to the consumer member with a career background related to research, medicine or clinical science. This culminated in a disagreement between a minority of 'vocal' group members, dividing those who felt that consumers with professional backgrounds lacked "*essential consumer qualities*" versus other members who felt that whilst professional consumers may bring different qualities to the table, they should still have a voice in research decision-making.

A further point advanced by those espousing normative frameworks for involvement, was the fine line between drawing on one's personal experience in a constructive manner for the benefit of the research group, as compared to those who used their personal experience in an unhelpful way. 'Preconceived agendas' and 'banging their own drum' were both used to describe the lay participant who consumed too much time within a research group talking about their own experiences. For example, Louise (professional, LRP) gave an example of a professional group that she had offered advice to about involving consumers in research:

"Well for example, the panel knew that they had to have a consumer involved and having had consumers involved in our study, you know, I talked to them about our experiences and a lot of people were very dismissive of the potential of the consumer and were concerned about confidentiality issues and all sorts of stuff and just thought that people would come banging their own drum rather than willing to listen to what was going on and to participate in the discussion actively".

Similarly, Sheila (patient, LRP) spoke of consumer members with personal agendas as potentially alienating the consumer role in research decision-making settings:

"You can't go with a preconceived agenda, that's not on. And that's why some people would not be very good at sitting on these meetings because they would want their own personal agenda to the front all the time and actually talking about themselves, not generically as a patient voice. And that's very important because once you start, it becomes personal, you won't get a hearing and you certainly won't last on that committee and then it makes it bad for other people, who will come after you".

From this, it appeared that many lay participants associated objective contributions, free from emotional or subjective appeals, as the preferred mode of behaviour within a research decision-making setting. Again, this follows the privileging of reasoned argument and makes claims about how life-world contributions should be set within clearly defined boundaries of what is considered to be acceptable. In other words, participants were making the case for setting boundaries around the articulation of one's experiential expertise:

"So the ability, people need the ability to step away from their experience, not to lose it because that experience is important, but to step away from it and to be able to listen and to relate what is being discussed to their own experience and bring the two together in a more constructive, critically constructive way" (William, patient, CSG).

As Barnes (2008), in her arguments concerning 'passionate participation' of the public involved in consultation groups, discusses emotion is surely a central feature of experience? Consequently, within the CSGs and the LRP the rejection of, or the boundaries placed around, the expression of emotionality often resulted in seemingly difficult personal reflections and what appeared to be an ongoing attempt to identify one's tangible contribution to research. This is illustrated quite clearly in the extract below, taken from an interview with one of the consumer members of the CSG subgroup, Clare (patient):

"Clare: But of course I have to be aware that I have to maintain objectivity. So it must inform my response but it must not be too much about my own experience.

Interviewer: How do you do that?

Clare: I have to be very careful and think about it carefully. There's always a desire to want to go 'it's been like that for me'. It's about not having one's own agenda. I have to be objective, and yet use my own background. So in a way it's more complicated and more demanding than for the researcher because one can be objective. So I have to use my experience although not emotionally in that it might skew my response...That is something I must remember, I'm there because of

my experience but I won't become too personally involved. You know to contribute out of one's experience but objectively not emotionally. Which goes back to the importance of training. I've benefitted from the training provided by the NCRN, previously from [a local cancer network], also from the Macmillan training and of course previously from the Community Health Council training as well. It is important and it's equally important for those involved professionally to go back and refresh, have refresher training to remember that we have to stay on that, you know the clear path between patient and professional. We're in the middle... That's my commitment to try and remain always objective but yet influenced by, motivated by, but not overcome by my experience. In other words it's using it effectively".

Similarly, within the LRP, the Chair was observed to make consistent requests to the group, asking members to refrain from appealing too heavily to their personal stories in group meetings and when undertaking research related activities. This was often framed within a commitment to prevent the LRP being identified by the wider research community as a group of (in the Chair's own words) "whingers and moaners".

From this, it would appear that it was increasingly necessary for lay members to understand where the line for an appropriate contribution could be drawn. There was a clear association between legitimacy, professionalism and objective behaviour. The association of research decision-making spaces with 'neutral, objective or dispassionate' argument may serve to block consumer members from drawing on their personal experience. An assumption here would be that lay members should have a highly sophisticated level of reflexivity in order that they bring together both the technical scientific world and the life-world perspectives in order to make a contribution towards research discussions.

7.3. Training as a form of system/life-world antagonism

As already explored, additional justifications for consumer involvement in research, over and above experiential knowledge, were apparent in consumer and professional accounts. As part of this, the reflexive positioning of lay participants within the interplay of system and life-world aims highlights the ambiguous nature of experiential claims to credibility and the difficulties that some lay members encountered when attempting to conceptualise their role and place in research decision-making forums.

As previously outlined, within the NCRN, there is a strong commitment to providing continual training opportunities for consumer members of both national and local research groups. Consumer members of the case study groups were provided with a regular programme of training. Training in research methodology played a central part of the LRPs function. During the year in which data were collected, the LRP organised three 'in house' training sessions for their members, in addition to members attending outside training events. Some of the lay members of the LRP and the CSGs (and subgroup) spoke of the value of training to help them gain confidence. For example, during a conversation with one member of the LRP, she told me how she would feel better about her role conducting lay peer review for a National research funding body if she could have some statistics training. Training also appeared to reinforce a personal sense of legitimacy. For example, during my observation of CSG2, when talking to the wider group about her involvement in a research study one of the consumer members appeared to place great emphasis on the research training that she had completed prior to commencing her involvement, adding that she wanted to 'do it properly'. Thus, one could assume an emerging link between undertaking research training and achieving a legitimate voice in research.

Within the LRP, the transition towards a more systematised approach for lay involvement in research appeared to be acknowledged by the LRP secretary, (Jean) when she described how the consumer members are now able to add more than a patient's perspective to the research process:

"So it's a change in what the panel were doing in the first place where people were going purely as patients. Now people are going onto these [research projects] and putting a bit of a research view, a view from a different perspective I think now".

Equally though, the increasing systematisation of the LRP was perceived to be potentially problematic by some participants. For example, Jean told me how she felt that the Chair of the panel had changed the format of the LRP meetings in order to formalise his role, in her own words 'skewing the original format of the panel'. By this she was referring to the increasing number of training days that the Chair organised for panel members and his, often verbalised, desire to establish the panel as a legitimate research group. In many ways, the inherent tension within the LRP was perhaps reflective of the multiple functions that it seemed to serve for different members. This

tension was found to be most stark between the social and the potential career functions that the panel fulfilled, often played out in a tension between system and life-world aims. Indeed, the increasing emphasis on training was perhaps the most apparent mechanism for maintaining the professional focus of the meetings.

As found within the CSGs, within the LRP, there was an emerging impression that a perceived sense of credibility was associated with undertaking training. This served to create a divide between those who had undertaken training and those who had not. Training, it seemed, had become a prerequisite for effective involvement, essentially undermining the legitimacy of LRP members based on their experiences of illness or caring. On more than one occasion, I observed members who had not taken part in the training question their own abilities to be involved in research and ultimately the contribution that they could make within the panel. For example, one LRP member (a carer) appeared to become increasingly despondent throughout the duration of the data collection year, at one point confessing that she was considering leaving the panel as she felt that she had nothing to contribute because she had not engaged with the training that was on offer. In this way, the discourses associated with training might be considered as a form of governmentality. Training comes to be framed as more than just beneficial and desirable, but increasingly essential if one wishes to be involved in health research. Involvement in research accordingly becomes less about widening participation and opening up expert systems to the public gaze, and more about the systematisation of a minority patient and carer population.

However, from the findings it would also seem that some of the consumer members were openly resisting the construction of the 'professionalised consumer'. For example, during a LRP training day in peer review skills and basic research methods, some members expressed an interest in finding out more about statistics. In response to this, one member made clear their resistance by stating "*we are here as people in our own right, not to be experts in statistics...*" At a different meeting (4 months prior), the same consumer member had spoken about the difficulty of '*knowing one's boundaries*' and '*where to bring in your experience and where (and how much) knowledge and medical knowledge to bring in*".

Consequently, it would seem that many consumer members continually reassess their position within the research arena, at times openly conceptualising (and re-conceptualising) their role in relation to system and life-world aims. This highlights a fundamental ambiguity within the discourses concerning public involvement in research.

7.4. Representativeness of consumer members involved in research

Arguments concerned with notions of representativeness of the consumers involved in research were raised by professional and consumer members alike, and were used to both confirm and undermine consumer claims to credibility within research decision-making spaces. For example, whilst the majority of the professional participants rationalised the consumer role in research based on their experiential knowledge, and thus an acceptance of the credibility of life-world accounts, at times this was also used to cast doubt over their consumer legitimacy in terms of their representativeness. This can be seen within arguments that sought to undermine consumer contributions to research based on their inability to represent a wider range of consumer perspectives. For example, when talking about the difficulties of consumer involvement in research, Shona (professional participant, CSG5) spoke of the unrepresentative nature of the consumer members:

"One of the things that has struck me with the few people we've had as patient advocates, patients on the CSG is that they probably are not very representative of the patient population as a whole" (Shona, professional participant, CSG5).

However, calls for consumer members to reflect experience and views beyond their own appears to contradict the experiential expertise rationale for involvement. Indeed, it seems to suggest that consumer members should be responsible for obtaining wider views beyond their own: a role that professional participants' are not obliged to do. This contradiction was clearly identified by one member of the CSG Secretariat, Helen:

"I don't think you can represent the group. I think you can be a voice who is a voice of a consumer with particular views but there is no way that the sarcoma representatives can represent the views of the whole of sarcoma [for example]. They can give some anecdotal evidence from the group of patients they come into contact with, you know fellow cancer sufferers or carers, but they can't do it because they can't go out there and canvas the views of every sarcoma

patient and carer in the whole of the UK. So I think that, just as we actually say, in fact I actually say to consumers, I do, is that people are appointed in their own right, so they're appointed for their specialism and their background, they're not there as a representative. So the scientific members don't represent their institution or clinical oncology per se. They are an individual with experience and a background in oncology which is needed for that group at that time. And I think the same has to be true of consumers. And therefore I think the word representatives ought to be dropped and it's a consumer member as opposed to scientific member" (Helen, CSG Secretariat).

From Helen's account, the consumer member can be viewed as 'just another voice' amongst the research group, contributing to a plurality of expertise, experience and specialist interests. Equally, amongst the consumer members' concerns were raised about their relative representativeness. For example, a few consumer members spoke about how the advertisement of consumer positions for the CSGs was potentially exclusionary, given that they were frequently limited within broadsheet newspapers. As Anne (patient, CSG1) reflected, "...only certain people read *The Guardian* don't they?" In this way it was assumed that the consumer recruitment process targeted a particular substratum of the patient/carer population; namely white and middle class. Ruth (patient, CSG) supported this point:

"I mean they're cherry picking people really, I mean if you look round, putting an advert in the guardian, what sort of people are you going get? I mean it's very biased, awfully biased" (Ruth, patient, CSG).

However, the increasing formalisation of the recruitment process was sometimes viewed in positive terms, essentially enhancing a consumer member's sense of legitimacy with a CSG. One established consumer member who had not gone through a formal process exclaimed:

"Why wasn't I asked to go and be interviewed for that post? I feel that we should be. We should go meet them and at least even then we feel as though we're there by consent" (Shirley, carer, CSG).

Therefore, it is possible to identify a further ambiguity emerging from the data: the development of normative frameworks and 'ideal' consumer member behaviour, skills and knowledge contrasted with concerns about the representative nature of the consumer member role. Whilst the advertisement process may 'cherry pick' certain types of consumer in a rather explicit manner, the normative frameworks serve to further reduce consumer involvement to a select few, but in a much more subtle manner.

This is essentially played out alongside further difficulties, or a grey area, concerning how a consumer member should position themselves within a research group. For example, whether a consumer member is part of a research decision-making group as an individual, or whether they should represent the wider patient population. Similarly, critical assessment (by both professional and the lay participants) of the representative nature, or 'laity', of consumer members due to their backgrounds, careers and training adds to this tension.

Clearly, the arguments concerning the representative nature of consumer members involved in research are illustrative of wider contradictions and ambiguities regarding the role and place of experiential knowledge. Issues of representativeness highlight, not only the uneasy distinction between 'lay' and 'professional' positions, and the relative 'grey area' that lies between these, but also the ambiguous nature of involvement based on varying (often competing) rationalisations.

7.5. Summary of Chapter

In the current chapter I have considered emerging themes relating to the construction of credible expertise. I have highlighted the way in which 'traditional' forms of certified expertise are privileged amongst the consumer members, often maintaining or reinforcing patient/professional divides. I have outlined three principal justifications for public involvement in research derived from the data: experiential knowledge (or extra scientific); scientifically engaged and normative frameworks for involvement. The findings indicate that professional participants most commonly construct the experiential knowledge rationale for consumer involvement in research, but this justification has been advanced to both validate and undermine the role of consumer members in research decision-making. Similarly, arguments concerning the representational authenticity of consumer members add to the debate over the epistemic, value driven and democratic rationales for involvement.

Whilst experiential knowledge constituted one of the most common initial claims for credibility given by the consumer members, a number of other claims subsequently emerged from the findings. The scientifically engaged model and the normative frameworks for involvement appear to undermine

the legitimacy of experiential knowledge as participants begin to associate the credibility to be involved with a set of skills and attributes *over and above* experience.

Certainly, the training offered to consumer members within the NCRN appears to contribute towards the development of interactional expertise and thus the scientifically engaged model of involvement. Accordingly, this appears to add to an account of credibility based on consumer member's abilities to communicate effectively with the scientific experts. It could be argued that this is a form of 'proto-professionalization' (De Swann, 1990; Shaw, 2002), whereby consumer members of expert committees adopt the terms and concepts of the expert group in order to secure acceptance. This in turn blurs the boundaries between expert and non-expert.

A continuum of expertise for consumer involvement has been suggested. It would appear that rather than a static hierarchy, many consumer members move along the continuum as they undertake further training, whilst other members can be seen as actively resisting this. In addition, the findings have demonstrated how notions of the 'professionalized consumer' were viewed by lay participants as potentially problematic, as they appeared to grapple with the usefulness of expert training, versus the loss of 'freshness', or a loss presumably of the primacy of experiential expertise.

Consequently, the construction of credibility within the discourse of public involvement in research is seemingly fraught with complexities. Far from a simple task of bringing the voice of the life-world to research spaces, consumer positioning appears to be a consistent source of confusion and conflict, with consumers seemingly involved in a continual (re) assessment of their role and place.

In the next chapter the key themes presented in the findings chapters will be explored in more depth. Drawing on the previous findings chapters and the wider literature I will consider the key policy claims regarding public involvement in research in the light of the research findings. Specifically, given the inherent ambiguities concerned with the construction of the consumer perspective and indeed how these are mobilised and integrated within the case study groups the following key claims regarding public involvement in research will be addressed:

- Public involvement in research as a form of deliberative democracy, based on the 'different perspective' that the public are said to bring to research.
- Public involvement in research as an empowering mechanism for the public.

Furthermore, grassroots claims to the development of consumer groups will also be addressed, including the potential for the NCRN consumer group to present a collective identity claim, a distinct epistemological claim and a political claim within research.

Part Three

Chapter Eight

Discussion

8.1. Introduction

How might we think about the policy and practice of public involvement in health research in the light of the empirical research findings from this study? Chapter two explored key health policy claims for public involvement in health research. These included: a democratic claim, based on public involvement in healthcare and research as a mechanism for opening up expert decision-making spaces; an accountability claim, based on public involvement in healthcare and research as a mechanism to strengthen public trust in expert systems; an empowerment claim based on public involvement in healthcare and research as a mechanism to 'empower' the public; an epistemic claim based on the 'different perspective' that the public bring to health research and lastly, a quality claim, based on the practical contribution of the public to health research.

Bearing in mind these contrasting claims for involvement, this study began with the aim to investigate the practice of public involvement in health research. Specifically, this involved exploring public involvement in the National Cancer Research Network. Two distinct settings where public involvement was taking place in the NCRN were explored. The first concerned consumer involvement within the NCRN Clinical Studies Groups (and subgroups) – representing the primary forums for initiating, discussing, developing and monitoring research within the NCRN. The second approach to involvement that has been explored is a Local Research Panel, which reflects a local approach to public involvement within the NCRN.

The research set out to explore the following questions:

- How do the 'involved public' and professionals rationalise and account for public involvement in health research?
- What roles do the public play in health research?
- How is the voice of the public integrated into health research spaces?
- What counts as credible expertise in research decision-making groups?

Having described the empirical findings regarding consumer and professional motivations for involvement (chapter five), the practice of consumer involvement in research (chapter six) and participant's epistemological rationalisations for involvement (chapter seven), this chapter seeks to bring these findings together and discusses the key health policy claims concerning public involvement in research in the context of my findings. The chapter will begin by reflecting on government policy for public involvement in health research (in England), and will consider the extent to which public involvement in health research can be seen as part of a development in deliberative democracy. As part of this, the arguments concerning public involvement in health research as a means of restoring public trust in expert systems, strengthening professional accountability and ensuring transparency in expert systems will be considered. Furthermore, the empowerment claim for public involvement in health research will also be explored in relation to the empirical research findings. Finally, the chapter will draw on the 'grassroots' literature concerning public involvement in health research and reflect on this in relation to consumer involvement in the CSGs and the LRP.

8.2. Consumer involvement in the NCRN as a deliberative ideal?

As discussed in the literature review, the involvement of the public in healthcare decision-making and research can be viewed as part of a development towards deliberative democracy (Barnes et al, 2006; Martin, 2008). According to this argument, traditional (sometimes referred to as 'elitist') approaches to public policy decision-making are regarded as inadequate, as they fail to take into account the pluralistic nature of societies and therefore contribute towards what is referred to as a 'democratic deficit' (Barnes, et al, 2006; Pellizzoni, 2001) in public policy decision making. Furthermore, it is argued that more deliberative forms of decision-making in relation to public policy are necessary in order to address a number of developments in the increasingly complex relationship between science and society, including: the emergence of 'consumerist' ideals in the health sphere (Rhodes & Nocon, 1998); the expansion of technologies and health information that are readily available for access by the general public (Davies & Burgess, 2004); and what has been referred to as a 'legitimation crisis' within expert systems, leading to the deconstruction of universal scientific

claims to knowledge, and the consequent emergence of experiential expertise (Prior, 2003). Deliberative forms of decision-making in public policy have been posited as one response to the uncertainties posed by the above challenges to traditional (or elitist) approaches (Davies & Burgess, 2004; Habermas, 1987). More specifically, by involving the public in public policy (in this case, health research), those esoteric spaces where knowledge is created and debated are potentially 'opened up' to greater lay scrutiny, thus enhancing the legitimacy of these organisations or spaces (Pellizzoni, 2001; 60). Thus, in theory, public involvement in health research appears to be one mechanism for achieving this deliberative ideal, by encouraging the inclusion of patient/carer, or 'life-world', perspectives into 'systems' orientated decision-making spaces.

As outlined in the literature review, Habermas (1984) refers to 'communicative rationality' as providing a basis for achieving the ideals of deliberative democracy (Davies & Burgess, 2004; Hodge, 2005a; Pellizzoni, 2001). According to Habermas, only through the process of open debate, where group members are able to participate freely, where discussions are not distorted by power (or what he refers to as an Ideal Speech Situation), can such a deliberative ideal be met (Godin, et al. 2007; Habermas 1984). Building on this, Davies and Burgess (2004) point to two fundamental principles that need to be in place to ensure effective deliberation takes place; these are competence and fairness. Competence concerns one's credibility to speak – to be seen as a credible source of information, or the degree of 'truth' that is associated with an individual's claim (Davies & Burgess, 2004). Fairness is concerned with whether a range of voices have been involved in this process, in other words, the representativeness debate. In order to explore the deliberative democracy claim in relation to consumer involvement in the NCRN, the next section will reflect on these principles, beginning with the issue of competence.

8.2.1. Issues of competence: constructing the credible expert in research decision-making forums

Chapter seven clearly illustrated the centrality of competence and credibility in relation to professional/consumer interaction in research decision-making settings within the NCRN. Based on this, it seems reasonable to claim that

successful consumer involvement in health research rests on the credibility claim of each participant and the acceptance of those claims by the wider group (including of course the professional researchers). If a participant's credibility is thought to be compromised, the validity of their contribution to the group will be questioned. However, in chapter seven the problematic nature of consumer competence and credibility was highlighted. This will now be explored in more detail.

The construction of what counts as credible expertise for consumer members involved in research is undoubtedly an ambiguous area. On the one hand, as chapters five and seven show, the majority of consumer members appeared to initially construct their contribution to research in terms of the 'different perspective' that they could bring. Within many of the consumer members' accounts, this 'different perspective' was seemingly rooted in consumers' personal experience of illness, treatment, or caring, which echo those constructions of 'experiential knowledge' (Flinterman et al, 2003), 'lay knowledge' (Popay & Williams, 1996; Williams & Popay, 2001) 'lay expertise' (Martin, 2008; Popay & Williams, 1996), and the 'life-world' (Habermas, 1987), that have been discussed in the literature review. For example, in chapter seven a number of consumer rationalisations for consumers' contribution to research were explored, including; Alan's (patient, CSG3) 'firsthand experience', Jenny's (carer, LRP) construction of the 'different viewpoint' and the 'real person' and Fiona's (patient, LRP & CSG) suggestion of the 'worldliness' that consumers can bring to research. Likewise, many of the professional participants' initial rationalisations regarding consumer involvement in research were grounded in claims around consumer's experience of illness, treatment or healthcare services (either as a patient or carer), with consumer perspectives sometimes suggested as providing an evaluative role within research based on their personal experience. For example, Joanne (professional, CSG4) spoke of the consumer role in research as providing assessments of the acceptability of research proposals, whilst others referred to trial recruitment and issues around consent and information.

Building on this, it was also apparent that some of the professional and consumer members regarded consumer involvement in research as providing a counter perspective, or a balance, to the professional perspective. For

example, Steven (professional participant, CSG4) spoke of the consumer in providing a '*checks and balances*' role, and Lisa (professional participant, CSG subgroup) described the consumer role as providing a '*reality check*' and suggested that their presence prevented over reliance on technical terms and jargon. Furthermore, in chapter five it was shown how some professional participants suggested an instrumental role for consumers in research, with consumers acting as advocates for health research and contributing towards greater public acceptance of clinical trials and health research more generally. Drawing on Habermas' (1987) 'system/life-world' dichotomy, one may therefore conceive of the consumer role in research as a way to re-couple the life-world and the system. Indeed, this initial analysis would appear to support to claims, such as those made by INVOLVE (2003), that point to the value of researchers engaging with the 'different perspective' offered by the public in order that research has relevance and meaning amongst the wider patient/carer/public population.

Accordingly, many of the initial constructions of the consumer role in research appear to be suggestive of Dyer's (2004) 'extra scientific model of public participation', with the consumer role primarily constructed as the provider of 'social assessments of science' (Dyer, 2004; 341). Yet on the other hand, whilst experiential knowledge was almost always provided as an initial claim to consumer credibility, by consumer and professional members alike, as participants' reflected on their own unique position in a research group – either as a professional or a consumer, further caveats regarding consumer competence and credibility in research often emerged. Firstly, as discussed in chapter seven, some of the consumer and professional participants suggested additional technical and certified knowledge and/or skills (beyond experience), as important elements for effective consumer involvement in research. In chapter seven, I argued that these form part of a 'scientifically engaged model for involvement' (Dyer, 2004). For example, those consumer members with clinical backgrounds tended to directly refer to their clinical expertise when talking about their role in research. In chapter seven, Sheila (patient, LRP) talked of wearing '*two hats*', when reflexively considering her dual positions in research, drawing on both her 'experiential knowledge' and 'certified knowledge'. In this case, I suggested that Sheila's medical certification provided her with 'referred expertise' (Collins & Evans,

2002); in that she could sometimes apply her clinical practice based knowledge to clinical research settings.

Furthermore, chapter seven also highlighted how some consumer members developed what can be called 'interactional expertise', readily engaging with the available training courses and the techno-scientific discourse. Moreover, it was apparent that many of the consumer members and some of the professional participants increasingly regarded interactional expertise as an important prerequisite for successful consumer involvement in research. For example, it was illustrated how Peter (professional participant, Chair, CSG3) suggested that consumer members should be familiar with organisational operations and medical terminology. Likewise, Ruth (patient, CSG), Robert (carer, LRP & CSG) and Sheila (patient, LRP) spoke of their enhanced capability to be involved in research due to their interactional expertise, improved through their engagement in the available training. This suggests an association between conversing in 'systems talk' and being accepted as a competent and credible member of a research group. There is some congruence here with Epstein's (1995, 1996) research that highlighted the way in which HIV/AIDS activists engaged in the language of medicine in order to establish themselves as credible experts within a professionally dominated field. As Epstein (1995; 417) states:

"While activists have also insisted on the need to bring 'non-scientific' language and judgements into their encounters with researchers, they have nonetheless assumed that the capacity to speak the language of the journal article and the conference hall is a sine qua non of their effective participation".

It would seem that there are important parallels between Epstein's (1995, 1996) study of HIV/AIDS activists and the accounts of consumer members in my own research, in relation to the construction of credibility and lay participation in research. However, my research highlights some distinct challenges associated with this 'scientifically engaged' model for involvement. Firstly, as technical skills and knowledge increasingly become a marker of consumer competence in research, some consumer members may be discouraged from participating in research groups if they have not undertaken the relevant technical training. In addition, chapter six illustrated how consumer members who had not attended training (either because they were unable or unwilling to do so) began to question their own credibility in

research and the limited nature of their experiential contribution (limited, at least, in terms of how it was received by others). Conversely, the findings from my research show that a number of consumers have become so proficient in the technical language of health research, that they now question their own authenticity as purveyors of life-world perspectives. This illustrates the difficult balancing act that consumer members had to negotiate in working within the area of health research. If, to be seen as a credible member of a research decision-making setting, consumer members need to speak the professional language, is public involvement in health research really fulfilling the democratic claim of opening up research decision-making to a plurality of voices, or is it just appealing to a particular kind of consumer who is able to articulate and integrate with the dominant language in these settings?

Interestingly, even when advocating the value of the experiential expert role for consumers involved in research, an additional set of necessary attributes of the 'right consumer', or normative frameworks for involvement, were suggested by both professional and consumer participants. For example, 'confidence' and 'intelligence' were often cited as essential qualities for consumer members, by both professional and consumer participants. However, there were also some inherent contradictions within these normative frameworks. For example, qualities such as 'freshness' and 'naivety' (suggested by both consumers and professionals alike) were often posited against the advantages of being an established group member with knowledge of the research system. Similarly, within both consumer and professional participant accounts there was a clear sense of confusion concerning 'how much' technical knowledge was useful for the consumer role versus the apparently inevitable advent of professionalization - when consumer members' 'layness' or critical edge were argued to be replaced with empathy for the professional members and the wider research system. Clearly, consumer involvement is a problematic and ambiguous activity.

Indeed, concerns over the potential for professionalization, expressed by both consumers and professionals, appear to be at odds with the construction of the scientifically engaged model and the normative frameworks for involvement. This disparity illustrates a further ambiguity that is seemingly embedded within the discourse of public involvement in

research. Consumer members appeared to be engaged in a complex process; reflexively identifying their role and their legitimacy in research on the basis of their unique contribution, and how this may integrate within a systems orientated organisation (importantly an organisation with which they clearly aligned themselves as working *with* rather than *against*). The complexity of this process was further highlighted in chapter seven when Clare (patient, CSG subgroup) was shown to claim a degree of objectivity, based on her ability to provide a perspective that was free from emotion, whilst at other times appealing to her subjective experience. Again, this appears to highlight the reflexive processes that some consumers are engaged in when trying to identify their role within a research decision-making group and their claim to competence and credibility within these groups.

In problematising the concept of 'lay health beliefs', Shaw (2002) points to De Swaan's (1990) arguments concerning proto-professionalization – the process whereby lay people internalise "*...the fundamental stances and basic concepts of the particular profession with which they are closely interacting*" (Shaw, 2002; 290). Arguably, the findings from my research indicate that in order for consumer members involved within the NCRN to play a role that is perceived by the wider group (both consumer and professional alike) to be valuable and useful, processes of proto-professionalization are central, if not inevitable. I would strongly agree with Shaw's (2002) argument and would suggest that the training that is offered to consumer members is essentially a form of proto-professionalization – teaching consumer members the *rules of the game* and contributing to the internalisation of the dominant discourse, whilst at the same time contributing towards the ambiguity concerning the role of the consumer.

Whilst chapter five revealed how the majority of professional participants were in favour of involving consumers in research, the practice of consumer involvement in research, as explored in chapter six, may go some way to elucidate the emergence of a scientifically engaged model for involvement and the development of normative frameworks for involvement. Specifically, within chapter six the analysis suggested that the integration of the consumer voice was far from straightforward. For example, clear examples were provided that illustrated how the voice of the life-world was sometimes included, blocked (overtly and covertly), disregarded and/or modified within

the NCRN CSGs and the LRP. Some CSG Chairs and group members were observed to explain technical aspects of the research meetings in plain English for the benefit of the consumer members, which appeared to facilitate greater consumer participation, in comparison with those groups that didn't explain the technical language. In contrast, the findings highlighted how some consumer members' attempts to achieve understanding, for instance by requesting a clarification of point, were openly blocked by the Chair or other group members. This was clearly illustrated in chapter six, when Paul (patient, CSG5) asked a question regarding recruitment to a clinical trial – and thus seemingly within the remit of the consumer role¹ – and was met with the Chair's response of "*I don't want to take up the committee's time*". Clearly, this scenario was far from an 'ideal speech situation', with Paul's 'life-world' contribution discounted in favour of achieving systems rationality. In this case, it would seem that the competence of the consumer member, Paul, as a credible member of the group, was evidently under question.

Thus, whilst chapter five revealed that the majority of professional participants stated that they were in favour of involving consumers in research in principle, in practice the general consensus appears to dissipate. Furthermore, chapter five highlighted that whilst some of the professional participants identified an intrinsic value to consumer involvement in research, others were motivated to involve consumers in research because of the procedural good associated with it, in other words in order to fulfil governance and organisational requirements. For example in chapter five, Victoria (professional participant, LRP) spoke about evidence of consumer involvement in research as increasing the potential for research to be funded. Furthermore, Matthew (professional participant, CSG) spoke of the organisational pressure for researchers to involve consumers in research. The credibility of the consumer role in research was thus often located in their necessary involvement to meet systems aims. Likewise, it could be argued that those professional participants who advocated consumer involvement in research as a technique to promote clinical trials and increase recruitment to clinical trials (as shown in chapter five), were also motivated

¹ For example the NCRN (2008) describe the consumer role in bringing the 'patient and public perspective' to the CSGs, whilst the INVOLVE outlines the role of the public in 'bringing a different perspective to research' (Hanley et al, 2004).

in terms of a systems rationality. These findings appear to support White's (2000) claims that consumer involvement in healthcare can be mobilised in order to achieve strategic aims rather than promote the inclusion of life-world perspectives. In a reflection of lay participation in Canadian local community health and social service centres, White (2000:477) concluded:

"Lay participation as it is preached and practiced is clearly about administrative and political efficiency, not democracy, consumer empowerment, or community control. It derives its value principally from its role as an administrative strategy".

At the other end of the scale, in chapter seven a minority of the professional participants were shown to openly reject any role for consumer members in research decision-making groups, with one professional participant referring to public involvement in research as potentially 'disastrous' and the possibility that consumers may 'interfere with the function of the group'. The implication here is that for some professional participants the realm of technical decision-making remains reserved for certified experts, and experiential expertise does not appear to qualify. In a study of university researchers' attitudes to public involvement in health research, Ward et al (2009) suggest that epistemological dissonance with regards to lay knowledge was a commonly held attitude amongst the participants. By this, Ward et al (2009) argue that researchers in their study:

"...constructed consumers as docile or vacuous bodies just waiting to be filled by academic knowledge..."

Furthermore, Ward et al (2009) claim that such an attitude towards lay knowledge may form part of a 'professionalising strategy' employed by researchers to:

"...maintain their power/status and promote the authenticity and primacy of their knowledge vis-à-vis consumer or lay knowledge".

This analysis may go some way to explain why some professional participants in my study openly rejected the involvement of consumers in research settings.

The variable (and often problematic) nature of the consumer role in the case study groups, and indeed the rejection of the consumer role in research by a minority of professional participants, may provide one explanation for the development of additional claims to consumer credibility, over and above experience. Furthermore, chapters five and seven indicated that for the majority of consumer members, competence and credibility in research decision-making settings were more commonly associated with 'certified' ways of knowing, over and above experiential forms of knowledge. Indeed, it would appear that within the NCRN many participants (both professional and consumer) viewed experiential knowledge as largely inferior to certified forms of knowledge. This was surmised from the noticeable emphasis that many of the consumer members placed on undertaking training courses. For example, chapter seven illustrated how consumer members frequently sought out additional training in scientific skills, associating such training as a necessity for the role of a consumer member. As part of this, some of the consumers spoke of the importance of training in order to enhance their ability to '*interact with professionals*'. It was apparent that some consumer members felt that they needed to engage with systems rationality in order to be heard within these spaces. The completion of training appeared to provide credibility and act as a signifier of competence in this domain. Again, this suggests we might want to treat with considerable caution the notion that experiential expertise alone was a sufficient prerequisite for credible involvement.

Congruent with my research, Kerr et al's (2007) study of public science (genetics) events, whereby researchers and the public were involved in public debates about the social aspects of genetics, also highlighted how the public were 'highly deferential' to professional experts and expertise. A similar point could be made with reference to my research. It could be argued that as part of the interview process consumer members in my research were engaged in an ongoing process of reflexive role reconstruction. Their deference towards expert systems and certified expertise may highlight a perception that consumer members needed to assimilate with the dominant discourse (the techno-scientific language) in order to be heard and understood within research decision-making groups. The way to achieve this was by addressing the wider professional group in the professionals' own terms (i.e. undertaking research courses and learning the language of trial

design, statistics, qualitative research and so forth), thus accounting for the development of additional credibility claims amongst consumer members. Interestingly, it was not the case that any professional members thought it important to 'understand' the consumer perspective in any greater detail by seeking to undertake training courses which facilitated a better understanding of the consumer or lay perspective.

In contrast, chapter seven also highlighted how a minority of consumer members displayed resistance to opportunities for technical training. For example, such resistance was shown to result in a number of group discussions amongst members of the LRP, as they grappled with their role and contribution to research. However, whilst one consumer member of the LRP was observed to strongly oppose the provision of technical training, claiming that consumer credibility should reside in experience rather than knowledge of statistics, in chapter seven it was discussed how this member gradually withdrew from the LRP, their attendance at meetings became increasingly sporadic and they eventually ceased having any involvement. Clearly, questions remain unanswered about the link between this particular member's notable opposition to the technical training and their withdrawal from the group. However, it is interesting that the consumer member in question was clearly part of a minority in their opposition to the group's normative ideals.

Consequently, it is clear that ambiguity and tension over the nature of the consumer contribution to research were paramount. In terms of the first principle for effective deliberation, as suggested by Davies and Burgess (2004), the findings from this research would suggest that issues of consumer 'competence' and credibility in health research groups are far from straightforward. Moreover, it would seem that experiential knowledge alone does not suffice in order for most consumer members in the NCRN to consider themselves as competent and credible members of research groups, and in some cases for the professional members to consider the consumer contribution as valid or useful. It appears that consumer 'competence claims' are shaped by the research organisation, professional claims to authority and consumer members' own efforts to position themselves as a credible participant within a research decision-making space. Greater competence and credibility are seemingly associated with the internalisation of the

techno-scientific language and discourse. However, this process is also fraught with ambiguity as some consumer members clearly attempted to conceptualise and grapple with the point at which 'too much' technical knowledge might impact on their experiential contribution. Furthermore, such reflections were clearly problematic given the lack of specificity in the NCRN consumer role description, and indeed in health policy guidelines more broadly. As a result, it is apparent that many consumer members were engaged in a reflexive reconstruction of what it meant to be a consumer member of a research decision-making group and what constituted their competence and credibility within these groups.

The discussion will now consider the second principle for effective deliberative practices, as outlined by Davies and Burgess (2004) - that of fairness. According to Davies and Burgess (2004; 350) 'fairness', in terms of effective deliberative processes, refers to "*...the inclusion of as wide a range of voices as possible*". On the one hand, one could argue that public involvement in itself is an exercise in widening the range of voices that are included in research decision-making groups. However, the findings from this research would support those from other studies that suggest that the 'involved public' constitute a minority group of the wider patient/carer population, thus raising questions about just how wide the 'range' of voices in research actually is (Campbell, 2005; Martin, 2008).

Consumer membership of the NCRN can certainly be considered as 'typical' of the public who become actively involved in forms of public committee and decision-making forums (Campbell, 2005; Martin, 2008). In my research the preponderance of consumer members from white, middle class backgrounds, primarily aged over fifty years, appears to reflect what Martin (2008;50) describes as the '*archetypal 'active' citizen*'. Thus, the arguments concerning the limited representation of patient views, that are often provided as a critique of public involvement in health more broadly, can be applied to consumer involvement in research and more specifically in the NCRN (Boote, 2002; O'Donnell & Entwistle, 2004a, 2004b).

Perhaps unsurprisingly, the unrepresentative nature of consumer membership in the NCRN was occasionally voiced by some of the professional participants as an argument against consumer involvement in

research, with limited level of representativeness perceived as a weakness inherent in consumer involvement in research. As highlighted in the literature review, such concerns have been raised in other studies (Boote et al, 2002; Thompson et al, 2009). Interestingly, in chapter seven the empirical findings highlighted how such disputes over consumer representativeness were not just limited to the professional participants, with some consumer members shown to express concerns about the range of lay people involved in research settings. In one way, the findings reflect the ways in which the NCRN have attempted to formalise the procedures for consumer recruitment onto the CSGs. It could be argued that these standardised processes serve as *'symbolic operations that grant representative legitimacy'* (Contandriopoulos, 2004; 327). Yet, conversely it seemed that some consumers felt that the selection processes were biased, in terms of the type of people who were targeted, with Anne (patient, CSG1) referring to it as *'cherry picking'*. Another consumer member, Shirley (carer, CSG subgroup) felt that they would be granted greater authority within a research group if the selection processes for consumer members were on a par with those for professional membership of the NCRN CSGs and subgroup. Again, such arguments are indicative of the ambiguities inherent to public involvement in health research. On the one hand, clear normative frameworks can be seen to have emerged, with participants suggesting an ideal 'type' of consumer to be involved in research. Yet, on the other hand, some participants expressed concerns that the consumer role in research was undermined by the limited range of consumers that are recruited to be involved in research. There is a clear contradiction here and one that seems likely to continue to shape consumer members' experiences of participation.

Campbell (2005) suggests that the narrowing of credibility, in terms of who can legitimately make credible claims to participate in research, provides a rationale for professionals to ensure that they engage with *'the good citizen'* (Campbell, 2005; 695). According to Campbell (2005; 695), the *'good citizen'* is one from a *'higher socioeconomic status'*, who is *'well educated'* with *'time and money available'*. Importantly, *'good citizens'* are *'likeminded individuals, or, if they possess differences, they are rational and able to discuss their diverse perspectives in a calm and insightful manner'* (Campbell, 2005; 695). Moreover, it would seem that the *'good citizen'* is someone who is unlikely to rock the boat. Consequently, the current recruitment and selection of

consumer members could be viewed as an explicit decision by professional organisations to select only those consumers who will conform to the existing order (White, 2000). This would appear to contradict health policy claims that consumer involvement in research is concerned with 'an exploration of difference' (Farrell, 2004).

So far, the discussion has reflected on some apparent ambiguities with the consumer role in the NCRN and the basis of consumer credibility, raising questions about the 'democratic' rationale for public involvement in health services and research that is suggested in health policy. In the next section, the 'empowerment claim' for public involvement in health research will be explored.

8.3. Consumer empowerment

In the literature review it was shown that the term 'empowerment' is increasingly referred to across government policy with regard to public involvement in health, healthcare and research (DH, 2001; Hanley et al, 2004; Rhodes & Nocon, 1998; Wilson et al, 2007). However, as also previously discussed in the literature review, there are multiple definitions and various theoretical frameworks associated with (and often problematising) the term, 'empowerment'. Empowerment may be explored at a personal or a group/community level (Roberts, 1999). Furthermore, empowerment may be experienced by different individuals in different ways (Small & Rhodes, 2000).

The findings from this study are intriguing and suggest that involvement in research may be empowering for some consumers, but for different reasons. For example, at the level of personal empowerment, chapter five provided examples whereby some consumer members were heard to speak enthusiastically about their engagement with the scientific and medical literature as part of their engagement with health research, and furthermore how some participants explicitly stated that they thought this was an empowering experience - for example, Alan (patient, CSG3) was extremely positive about this aspect of involvement. In a slightly different vein, Jenny (carer, LRP) spoke of consumer involvement in health research as a mechanism through which patients' and carers' abilities to communicate with

health professionals may be enhanced. For example, increased knowledge of medical terminology and research, gained through involvement in health research, was argued to lead to greater consumer confidence when interacting with health professionals, and may be interpreted as potentially empowering. Such constructions suggest a personal level of empowerment, with involvement in research enhancing consumers' potential to speak out and have their views heard and respected (Small & Rhodes, 2000).

Engagement with forms of technical expertise, or the 're-appropriation of knowledge and control' (Giddens, 1991) by some consumer members involved in research decision-making, appears to correspond with late-modern accounts of individuals' reflexive engagement in the process of sense-making. For example, Giddens' (1991) suggests the notion of 'lay re-skilling', whereby lay people are said to re-engage with expert systems for the purposes of greater personal control and empowerment. Nevertheless, whilst lay re-skilling might be experienced positively by some consumers, it can also be viewed as an exclusionary device, potentially limiting the involvement of those unwilling or unable to engage with expert systems on this level, or those consumers who become involved in research on the basis of experiential expertise alone. For example, chapter six illustrated instances when consumer members of the LRP questioned their own value or worth within the group because they had not participated in the technical training that was on offer. In this case, it could be argued that processes of lay re-skilling may contribute towards the disempowerment of some consumers and may serve to widen the gap between those who had undertaken training and those who had not. This is discussed further in section 8.5.1.

For some of the other consumer members, involvement in health research appeared to provide an opportunity for the reflexive reconstruction, or narration (Williams, 1984) of their identities, and in doing so, calling into question traditional notions of patient passivity. As part of this, some of the consumer accounts of involvement in research resonate with Frank's (1995; 115) construction of the 'quest narrative', whereby patients are argued to '*accept illness and seek to use it*', thus retelling their illness narrative in a constructive manner, in this case with cancer prompting consumers' decisions to get involved in research. For example, in chapter five, William (consumer, CSG) spoke of wanting to get involved in research as he '*didn't*

just want to moan' about the treatment that he had received. William wanted to draw on his experiences of healthcare and use these in order to play an active role in research decision-making and have his views heard, which is also indicative of what Frank refers to as a quest narrative. Likewise, other consumer members provided altruistic motivations for involvement, such as Mary's (patient, CSG) desire to 'help others'. In chapter five, it was argued that such accounts may challenge simplistic notions of the healthcare consumer. Thus, consumers may be empowered through contributing to action and transformation (either at a personal/identity level, or at a wider health service level).

In spite of this, the findings also suggest that involvement in research should not be regarded as a universally empowering experience. For example, chapter six indicated that the consumer voice could be restricted within the case study groups, limiting the possibility for consumers to feel that they could make a useful contribution. In particular, an example was provided that illustrated how one consumer member of CSG5, Paul, was openly discouraged from making a contribution to the group discussion. Furthermore, a couple of consumer members professed to feelings of intimidation and inferiority within the wider professional groups. Indeed, chapter seven pointed to the way in which Anne (patient, CSG1) spoke of feeling 'utterly deskilled' when what she described as her own knowledge of her illness, or life-world understanding, was undermined in the face of professional expertise. Such accounts suggest that traditional paternalistic patient/professional relationships could sometimes be reinforced within the case study groups, regardless of the more active role that the consumer might be supposed to adopt within these groups.

Furthermore, in chapter five Ruth (patient, CSG3) was keen to point out her considerable sense of disquiet with the health policy emphasis on 'empowerment', and argued that as a cancer patient nothing could empower you. Ruth's account reminds us of the primacy of her patient identity (which applied to many of the consumer participants in this research) and her reliance on forms of medical expertise, which might have overshadowed other roles she might adopt. Moreover, Ruth's account also emphasises the contradictory nature of empowerment, which seeks to promote the 'active patient' within a medical framework (Wilson, 2001).

8.4. Summary of section

In the preceding sections, key claims made in health policy, concerning consumer involvement in research have been explored in the light of the research findings. I have argued that consumer involvement fails to meet the criteria given for a deliberative ideal for a number of reasons, including: life-world claims are often discounted by both professional and consumer members; consumers were highly deferential to certified knowledge; and consumer were engaged in professionalization processes.

More specifically, I have suggested that regardless of the rhetoric of the 'experiential expert', it appears that within the consumer group of the NCRN, many consumer members are actively involved in defining the boundaries of their own involvement and the terms of their credibility. These appear to be located within traditional certified models of expertise, suggesting the strong influence of these ways of knowing. As a result, I have queried the extent to which consumer involvement in research can be regarded as a mechanism for ensuring organisational accountability given the deferential role of the consumer. Therefore, whilst it would seem that there is a general consensus amongst the majority of participants (both lay and consumer) regarding the broad principle of involvement, this consensus breaks down as policy is implemented into practice and further clarity is required.

Whilst the current section has explored the findings in relation to the political approach, or the 'top down' drivers for public involvement in the research, I will now turn to explore the findings in relation to the grassroots approach to public involvement in health research.

8.5. Consumer involvement in health research as a health social movement

In the previous section, I explored the research findings in relation to key claims made within health policy. In particular, consumer involvement in the NCRN was explored in relation to the arguments for deliberative democracy, the re-establishment of public trust in science and consumer empowerment. In addition to the policy claims for involvement, in the literature review it was also suggested that public involvement in health research could be

regarded as a form of collective grassroots patient/carer action, or a Health Social Movement. These ideas will now be explored in relation to the research findings.

In terms of a collective identity, consumer members' experience of cancer (either as a patient or a carer) suggest a unique connection between members based on their personal experience, one which Rabinow (2002) labels as a 'biosocial link'. Brown et al (2004; 60) argue that whilst illness identity is often a personal identity, when patients and carers establish 'a *cognitive and emotional connection*' with other patients and carers, a '*collective illness identity emerges*'. My observations certainly point to a sense of group collective, particularly in relation to the LRP where a strong social/support function was apparent. It may be possible to account for collective consumer action in the NCRN as part of individuals' attempts towards sense-making. In late modernity, traditionally 'stable' institutions and social structures (e.g. religion, family etc) that were central to individual socialisation, self-understanding and identity appropriation are said to be increasingly susceptible to instability and change (Giddens, 1991; Nettleton, 1995). As a result individuals are argued to engage with alternative structures and organisations in order to fulfil these needs (Giddens, 1991). It could be argued that public involvement in health research provides one of these 'alternative structures' in which patients and/or carers can develop knowledge and understanding of their illness/caring circumstances. In particular, chapter six highlighted how the LRP appeared to provide a space where consumer members could sometimes engage in communicative rationality and share their illness/caring experiences. Yet, whilst the supportive function undoubtedly contributed towards a sense of unity within the LRP, fulfilling particular social and support needs in some consumer members' lives, arguably this also added to the confusion concerning the function of the panel. As an illustration of this, chapter six highlighted how some members of the LRP, in particular the Chair, were keen to maintain the research, or systems, focus of the group and control the amount of time that members spent exchanging stories and experiences. In contrast to this, other members of the LRP seemed eager to develop the supportive/self-help function of the panel, for example by creating a web-based discussion forum, and in this way claiming a greater life-world focus for the LRP.

Chapter five also pointed to some emerging collective norms and values amongst the consumer members involved in the NCRN. For example, commonalities in social background, values and ethics between consumer members were presented in chapter five. These included the civic interests of some consumer members, with Clare (patient, CSG subgroup), Alan (patient, CSG3) and Hannah (patient, CSG4) found to be active in voluntary sector organisations. Other consumer members were found to have an interest in research and service improvement as an extension of their professional selves, with consumer professional backgrounds including clinical work, social services, and scientific teaching. In addition, these collective values were coupled with relatively homogenous socioeconomic backgrounds between many of the consumer members. As previously explored, these findings loosely correspond with other work on public involvement in healthcare services and research, such as Epstein's (1995) study of the HIV/AIDS activist movement in America where he described the activists' high degree of 'cultural capital', in relation to the preponderance of middle-class, professional backgrounds amongst the activists. Campbell's (2005; 695) construction of the 'good citizen' (as explained above) also resonates with the findings from my study. Nonetheless, there were some exceptions to this, for example within the LRP group members were found to come from a wider range of socio-economic backgrounds.

Whilst there appears to be a case for an emerging collective identity amongst the consumer membership of the NCRN, such a collective identity was not unproblematic. For example, as previously discussed the processes of lay re-skilling and the emerging models of credible expertise highlighted some potential difficulties. Whilst the completion of technical training appeared to provide one way for consumer members to establish credibility within a wider professionally dominated group, this sometimes resulted in questions (from both consumer and professional participants) concerning the extent to which consumer credibility would be reduced, or moreover their patient/carer authenticity within a wider patient/carer population. The irony of this was not lost on Hodge (2005), who found a similar situation emerging in relation to mental health service user participation in mental health forums:

"...in order to engage with the system on its own terms and in its own language, mental health service users must possess skills which, by

their nature, serve to undermine the very identity that has given them their place at the table in the first place."
(Hodge, 2005; 170)

Indeed, the findings from my study indicate that whilst authority was given to techno-scientific rationality, this also contributed towards a growing sense of antagonism within the NCRN consumer groups. This was coupled with confusion over whether the consumer members' role was seen in terms of fulfilling systems or life-world rationality. In chapter seven, an example was provided that illustrated one LRP consumer member's confusion around *'knowing one's boundaries'*. Similarly, in chapter six a professional member working with the LRP was shown to be keen to prevent LRP members becoming *'mini researchers'* through the processes of technical training. Fundamentally, within the LRP there appeared to be a growing divide between members who were competent in scientific language, and were keen to engage with the training made available to them, and those who were not. At times, some consumer members within the LRP appeared to make active choices *not* to engage with the available training and were observed to clearly promote the value of life-world contributions in their own right, clearly illustrated in chapter six. They thus appeared to be resisting the power of what was seemingly the preferred mode of behaviour within the consumer group. Whilst on other occasions, the findings show how a small number of consumer members were unable to attend training sessions and as a result felt that their credibility and contribution to research was in some way lacking. For example, in chapter six the findings illustrated how one consumer member from the LRP, who had not undertaken any technical training, became particularly despondent and was observed to question their own role and place in research. This appeared to approximate to a process of *'self-surveillance'* (Foucault, 1977) with the member in question monitoring their own behaviour against that of the wider group. Similarly, within the CSGs and the LRP, group norms and values appeared to act as both an incentive for *'likeminded'* individuals to become involved, whilst also transforming the identities of those consumers already involved. Anne's (patient, CSG1) confession of her *'guilt'* motivating her to become more heavily involved in consumer involvement provided one example of this. As argued in chapter five, it appeared that Anne modified her behaviour, becoming more involved in research at both a local and national level due to the strong influence of the core consumer identity.

Consequently, this section has outlined the emerging consumer collective identity within the NCRN and suggested the problematic nature of this collective. The collective identity evident within the cancer consumer group can be seen as both encouraging participation amongst a specific subset of the public, either because their personal identities converge with the group identity (Snow & McAdam, 2000) e.g. 'engaging the good citizen' (Campbell, 2005), whilst also transforming, or extending other individual identities to fit within this core set. Whilst not carried out through explicit coercion, many individuals involved in the NCRN appeared to internalise standards and behaviours that are seen to be appropriate for consumer representation. Building on this, the next section will explore a second claim for HSMs - the possibility that consumer involvement may be regarded as an epistemic challenge to research, through the promotion of a 'different perspective'.

8.5.1. *Consumer involvement in the NCRN as an epistemic challenge?*

According to Habermas (1984), new social movement activity comprises groups of individuals who present collective forms of action with an aim to counter systems dominance and reintroduce elements of life-world rationality. As part of a 'legitimation crisis', it is argued that there is increased public scepticism towards the institutions of science and medicine and a decline in public trust of certified experts (Beck, 1992; Giddens, 1990; Irwin & Michael, 2003). Furthermore, much of the literature that addresses HSM activity makes reference to the potential *challenges* that these groups pose to established ways of working. For example, Hess (2004) talks of the 'epistemic challenges' that HSMs pose to medical knowledge and as a result the medical profession, whilst work conducted by Epstein (1995, 1996) on the HIV/AIDS activist movement (as outlined in the literature review) suggests that the HIV/AIDS activists sought to "*change the ground rules about how the game of science is played* (Epstein, 1996; 13)". The findings presented in my research, provide an interesting reflection on these ideas, illustrating that traditional certified forms of knowledge were held in high esteem amongst the majority of consumer members. For example, in chapter five primary motivations for involvement in health research for the majority of consumer members did not appear to be founded on scepticism, a distrust of science, medicine or their associated professions, nor were the

majority of consumers primarily motivated to take part in health research due to poor healthcare experiences or through a sense of injustice. Furthermore, whilst a small number of the consumer members did suggest that their poor experience of healthcare services or treatment had provided an impetus for their involvement in health research (as discussed in chapter five), their motivations to remain involved appeared to be primarily based on altruism, rather than a distrust of science and medicine. In contrast, as already discussed, it appeared that professional participants perceived consumer involvement in research as a mechanism to increase public trust in clinical trials, with consumers acting as advocates for research, promoting and normalising clinical trials amongst a wider patient/carer population.

Fundamentally, consumer members constructed their role in research as working *with* health professionals for the purpose of improving healthcare services and provision rather than *against* them or as a challenge to them. Therefore, the emphasis that is given to public or lay involvement as an 'epistemic challenge' (Hess, 2004) to traditional certified forms of expertise is perhaps where the NCRN consumer group departs from other forms of patient/carer activity in healthcare, services and research.

It could of course be argued that the inclusion of consumer members at research decision-making forums is in itself a challenge to traditional mechanisms of knowledge production. Indeed, in chapter seven the findings did indicate that a small number of the professional participants did agree that their working practices had altered as a result of the consumer presence. For example, in chapter five Louise (professional, LRP) explained how she had changed the recruitment strategy for her research as a result of consumer input, whereas Lisa (Chair, CSG subgroup) spoke of the '*profound change*' that consumer involvement made to the CSG subgroup with consumer members argued to 'bridge the gap' between professional members and the wider patient population. The extent to which these changes can be considered an epistemic challenge is, however, questionable. Other professional participants held strong attitudes that consumer involvement had no impact on health research. For example, James (professional participant, CSG1) clearly expressed his feelings stating that consumer involvement in research was of '*limited value*'. Furthermore, as already discussed, the extent to which consumer members of the NCRN can

be seen as presenting an epistemic challenge to the existing order is perhaps limited given that their experiential knowledge appeared to be so easily compromised in favour of certified expertise, or expertise that allowed them to converse with the professional researchers.

As such, rather than presenting 'an epistemic challenge' to research, it would seem that the consumer involvement in my study is perhaps less about consumers challenging the experts and more about working with the experts in the experts' own terms. These conclusions appear to dispute some arguments that have been suggested by other commentators about the epistemic challenge that lay knowledge can present in professional settings, such as Hess's (2004) suggestion that lay people present an 'epistemic challenge' in the field of complementary therapy, or the assertion by Williams and Popay (1994; 120) that lay knowledge provides a challenge to the 'institutional power of expert knowledge'. Rather, these conclusions appear to have some parallels with those found in different settings, such as a study by Kerr et al (2007) of lay/professional interaction in public forums concerning genetics. Highlighting the limited impact of lay voices in challenging professional expertise, Kerr et al (2007) conclude that they hold reservations about the possibility that lay involvement in scientific debate may lead to more transparent technical decision-making spaces, or more deliberative forms of knowledge production. Similarly, Davies & Burgess' (2004; 360) study of lay and professional dialogue in a forum discussing organ transplantation, conclude:

'...instrumental rationality and internalised deliberation can still be privileged in new deliberative spaces'.

In a different study, Weiner (2009) explored the merger of two heart health organisations (one patient led and one professionally led) and concluded that collaborative working between these two organisations was for strategic reasons, rather than a move towards democratising knowledge.

Consequently, if (as my study would suggest) lay credibility in research decision-making spaces rests on a desire to accommodate and communicate with the expert systems, the 'experiential' contribution within these spaces is rather limited. As such, rather than 're-coupling' system and life-world perspectives within research settings, it would seem that in many cases

public involvement in research may simply serve to extend the colonisation of consumers' life-world perspectives with professional/certified forms of knowledge and expertise.

Summary of section

In the light of the arguments presented above, I would argue that *certain* elements of the NCRN consumer group can be located within the culture of new social movement theory, as proposed by Habermas (1984). As a collective, the cancer consumer group appeared to display some of the core features of other collective patient organisations, such as the collective identity proposed by Rabeharisoa (2005), and those discussed by Allsop et al (2004), with their construction of 'Health Consumer Movements', Brown et al's (2004) 'Embodied Social Movements' and work by Epstein (1995, 1996) on the HIV/AIDS activists. There are certainly some elements of a collective value identity and consumer involvement in the NCRN seemingly appeals to a certain 'type' of cancer patient/carer. It is in relation to the idea of an 'epistemic challenge' that the cancer consumer group appears to depart from some other forms of HSM activity. Furthermore, the extent to which consumer involvement in the NCRN has resulted in the integration of life-world perspective is also open to debate.

8.6. Conclusion

In this chapter, I have reflected on the research findings in the light of health policy claims for public involvement in healthcare and health research, and the theoretical debates concerning the emergence of grassroots consumer movements in healthcare. Findings from my study appear to both support and challenge some of the ideas suggested by Giddens' (1991), in his reflections on the relationships between experts and society in late modernity. It is certainly possible to contend that the consumer members of the NCRN are engaged in what appears to be complex reflexive reconstructions of their own identities, their relationships with other cancer patients and carers and their association(s) with certified expertise. This was found in the development of a collective consumer identity, amongst many of the consumer members, pointing to the potential to consider the NCRN consumer group as a form of HSM. Yet, it was argued that this movement

was framed as 'working with' the certified professionals rather than posing a direct epistemic challenge. Furthermore, in working with the certified experts it was apparent that on occasion some consumer members' life-world perspectives were often prevented from being voiced within the CSGs and LRP. This occurred for a number of reasons; the structure of the organisation prevented opportunities for communicative rationality; some professionals chose not to engage with experiential knowledge; some consumer members developed their contribution to research beyond life-world claims, becoming 'scientifically engaged'; involvement in research was targeted towards, and appealed to, a particular subset of consumers.

In the light of this, it is possible to question some of the claims often found within health policy literature, and some of the claims made by organisations such as INVOLVE, that consumer involvement in health research offers the opportunity for different perspectives to be heard in research, or that consumer involvement is about 'an exploration of difference' (Farrell, 2004). In fact, experiential knowledge, as found in this study, may be perceived by some professional and consumer members as inferior ways of knowing. On the other hand, many of the consumer members in this study were open to developing technical skills and knowledge, by engaging in the available training. Consumer members' engagement with the available training was perceived by some to make them a more credible participant in research decision-making settings, and indeed a number of the professional participants also appeared to favour the 'trained consumer'. Whilst a small number of consumer members' were found to openly resist the technical training, and claim the importance of experiential knowledge, it appeared that they were in the minority. Furthermore, given the apparent ambiguity concerning the consumer role and credibility claim in research, tensions arose about how much technical training would be sufficient, with some consumer members and professionals querying the point at which a consumer may become 'professionalized' and lose their 'consumer' status.

In turn, we may begin to reflect on the possibility that consumer involvement in the NCRN may result in the integration of 'different perspectives' into research as health policy suggests. Indeed, we can return to the question posed by Stilgoe et al (2006; 19):

"Are we opening up expertise to new questions and perspectives, or are we just letting people see the experts at work?"

The findings from this study suggest that the answer to this question is both yes and no. Consumer involvement remains a highly ambiguous concept. Certainly, there were some examples of life-world perspectives voiced within some of the case study groups (as explored in chapter six). However, the findings presented in chapters six and seven indicate that such life-world integration was variable and often prone to compromise. Furthermore, at the level of direct involvement at a strategic level, such as the CSGs, it would seem that the consumer contribution can sometimes be limited unless they can speak the technical language of science, medicine and research. In fact, as the majority of consumer members had chosen to undertake additional training, or fell back on other sources to confirm their credibility within research, it could be suggested that they themselves had begun to query the limits to the experiential contribution in these systems orientated settings. Despite this, an argument was put forward by some of the professional and consumer participants that consumer involvement in research resulted in a degree of 'reality check'. This potentially suggests that the consumer presence in the CSGs and in local research teams via the LRP, may contribute towards small changes in professional practice. Furthermore, whilst it is apparent that involvement in research is often limited to a minority subset of patients/carers, the findings from this study suggest that involvement can serve multiple purposes, including social/support functions and the opportunity for patients/carers to reconstruct their illness/caring identities.

Having discussed the three empirical findings chapters and contextualised these within the existing body of literature, in order to reflect on the findings from the NCRN more broadly, in the next and final chapter of this thesis I shall provide some concluding thoughts on the research, the implications that this study may raise for policy and practice, and questions for future research. In addition, I will reflect on the process of undertaking this research, working with consumer groups and a lay advisor, my own initial assumptions on commencing the research and how these may have been confirmed, challenged or changed over time.

Chapter Nine

Conclusion

9.1. Introduction

In the previous chapter, the empirical research findings were brought together and discussed in the light of the key claims made in the policy discourse and wider theoretical literature regarding public involvement in health research.

In this concluding chapter, I will provide a brief summary of the main findings and contributions that this thesis makes to the existing literature. Firstly, I will begin by providing a brief summary of each of the findings chapters covered in this thesis and the key discussion points outlined in the previous chapter. Next, I will reflect on the potential implications that these findings may have for policy and practice and questions that have been raised as a result of this research or those that remain to be answered. Following this, I will reflect on some of the particular methodological considerations that were encountered and the limitations of this study. Finally, I will provide a reflexive account of the research process. This will include my thoughts on the research process, researching consumer groups and working with a lay advisor.

9.2. Summary of the thesis

This thesis set out to explore a broad set of questions:

- How do the 'involved public' and professionals rationalise and account for public involvement in health research?
- What roles do the public play in health research?
- How is the voice of the public integrated into health research spaces?
- What counts as credible expertise in research decision-making groups?

In order to explore these questions a qualitative approach to research was taken. Specifically, the research borrows from aspects of the ethnographic tradition, such as gaining depth and detail of a subculture, in terms of its function, the people involved and the social dynamics. Data for this research were collected through interviews, observation (both participant and non-participant) and documentary analysis with purposively selected case studies from the National Cancer Research Network. The findings chapters covered the following areas:

Chapter Four: In chapter four, the background and context to the case studies was provided. This chapter justified the selection of the National Cancer Research Network as the framework from which the case studies were sampled. Firstly, a theoretical justification for selecting the NCRN was made based on this network providing established cases of consumer involvement in research at national and local levels, allowing an exploration of the potential for structural differences between local and national cases. Secondly, a pragmatic justification was provided based on the willingness of key 'gatekeepers' within the NCRN to assist and work with me and the difficulties experienced in gaining access to the other clinical networks. Therefore, it was argued that the NCRN provided a sound sample population for exploring the research questions.

Chapter Five: In this chapter, the findings concerned with consumer and professional motivations for involvement were considered. Firstly, it was suggested that consumer members' motivations for involvement were based on life-world interests. It was clear that all consumer members were initially motivated to become involved in research due to their personal experiences of cancer (either as a patient or a carer). Using their experiences of ill health, treatment and care (good, bad or indifferent), consumer accounts suggested that effecting change, either to their personal circumstances, or to available health services, was their primary motivation for their involvement. Furthermore, it appeared that many of the consumer members found involvement to be an empowering experience, albeit in a number of different ways – pointing to the multifaceted nature of empowerment. In contrast some consumer accounts suggest that involvement was in fact disempowering, highlighting the complex and problematic nature of the empowerment claim for involvement found within health policy. It was also suggested that a collective group identity can be distinguished within the

cancer consumer group of the NCRN, based on members' socioeconomic backgrounds and a shared set of values and interests.

In contrast to consumer life-world motivations for involvement, it was suggested that professionals appear to be primarily motivated to involve consumers in research based on improving the 'success' of a project. This included achieving governance requirements, increasing the acceptability and uptake of a project, or in promoting and advocating research to a wider public audience.

Chapter Six: In this chapter the practice of consumer involvement in the case studies was explored and specifically how (or if) the voice of the consumer and their life-world interests are integrated into research systems. The chapter highlighted clear tensions in systems and life-world aims within the group. Most significantly, the findings illustrated how tensions between systems and life-worlds aims, or instrumental and communicative rationality, did not automatically equate to a professional versus consumer distinction. As such, it was argued that the consumer role in research is far from straightforward and furthermore that the claims for involvement based on the 'different perspective' that consumers bring to research were open to question.

Chapter Seven: Building on chapter six, chapter seven explored constructions of the consumer claim to credibility in research. It was argued that experiential knowledge constituted one of the most common *initial* claims for credibility given by the consumer members; a number of other claims subsequently emerged. Specifically, two models for involvement were suggested in this chapter based on constructions of consumer credibility interpreted from the findings. These were the 'scientifically engaged model' and the 'normative frameworks' for involvement. It is argued that these constructions appear to undermine the legitimacy of experiential knowledge, or the 'different perspective', as participants began to associate consumer credibility to be involved in research with a set of skills and attributes *over and above* experience.

Chapter Eight: In this chapter it was argued that policy claims for involvement based on the 'different perspective' that consumers bring to research are open to doubt. Furthermore, it was suggested that in some

cases this 'different perspective' vis-à-vis experiential knowledge may be perceived of as inferior ways of knowing. In this respect, it was argued that far from providing a form of deliberative democracy, or a mechanism for 're-coupling' system and life-world perspectives in health research, consumer involvement in research may serve to widen the inequalities gap between those who take part, i.e. constructions of the 'right consumer' or the 'good citizen' (Campbell, 2005) and those who do not. As part of this, it was apparent that some consumer members became disillusioned with involvement, questioning their own legitimacy in research spaces. On the other hand, for those consumers who do take part in research and willingly engage with the dominant techno-scientific discourse, it would seem that involvement allows opportunities for the reconstruction of identities based on the development of new skills and knowledge, engagement in a strong social collective and the opportunity to re-cast their cancer experience in ways that they perceived to be more constructive.

Fundamentally, it was apparent that consumer involvement in research as a policy directive is far from straightforward, it is fraught with ambiguity and tension as consumer and professional members attempt to forge a path forwards.

The next section will consider what these findings mean for policy and practice and suggests further research questions that need to be answered.

9.3. Implications for policy and practice and future research questions

In terms of the policy implications for public involvement in research, the findings from this study suggest that the opportunities for the public to have a voice in the research process, based on life-world concerns, are severely restricted. It was apparent that many consumer members were highly deferential to certified ways of knowing and, as such, the suggestion that public involvement in research may provide some balance, or a counter to professional dominance may be highly unlikely.

Whilst some commentators have suggested that these issues may be solved through the development of better guidance for professionals on how to involve the public in research, and more explicit role descriptions for lay

members involved in research (see for example, Dyer, 2004), I would argue that it is likely that tensions between systems and life-world aims would still exist, due to lay participants' apparent desires to engage with expert systems in systems terms. Furthermore, better guidance for professionals may have little impact if they are still driven by the systems rationality.

On the basis of this research, I recommend that policy developers need to reconsider the grounds upon which public involvement in research is advocated. If involvement is founded upon the inclusion of experiential (or lifeworld) knowledge, for the purposes of encouraging a plurality of perspectives into research decision-making groups, enhancing transparency and accountability, and improving the applicability and acceptability of research within the wider patient population, it is recommended that further work is needed to promote the role and credibility of lay knowledge and expertise in health research. My research indicates that given the apparent deference to certified knowledge amongst the consumer members, this work will be necessary with both lay and professional groups. Such reflection on the grounds for public involvement in research would invariably lead to a reconsideration of the training requirements for the involved public.

Only once a reconsideration on the grounds for public involvement in research is conducted, can we begin to address the ambiguity and develop guidance on the roles of the public in research. Furthermore, it is recommended that future policy developments consider the potential that current public involvement strategies may serve to widen inequalities gaps between those who take part and those who don't. The findings from this study supported claims made elsewhere that involvement in research appeals to the 'archetypal 'active' citizen' (Martin, 2008; 50). Certainly, if the aim of involvement is to encourage a plurality of voices in health research, it is necessary that the approaches taken for advertising roles for the public in research be revisited. Restriction to certain broadsheet newspapers may not present the best approach to encouraging diversity.

Furthermore, given the apparent motivations within the consumer group to engage with deliberative forums for the purposes of 'having a voice' and bringing about change, further thought should be given to mechanisms that would best achieves these aims.

More importantly, this research has begun to reflect on public involvement in research beyond an 'implicit good' to consider some of the intricacies, nuances and tensions that exist. I would argue that such critical reflection is necessary in order to assess both the purpose and practice of public involvement in research against the current practice.

In terms of further research, it would be interesting to repeat this study within the different disease specific networks in order to understand the extent to which these findings are specific to cancer or can be found outside of the NCRN. Appendix A includes findings from some initial interviews conducted within the MHN and DeNDRoN, which suggest that there may be some parallels between these networks, however further work is required in this area to begin understand this in any depth.

Given that the findings highlighted the impact that involvement had on consumer members' identities, it would also be extremely interesting to find out what consumer members go on to do once their term of involvement ends. For example, within the CSGs and subgroups, the maximum membership term is three years, plus a potential extension of a further two years. We have little understanding of what happens to consumer members once their membership in these groups has ended.

Furthermore, it would be useful to understand why some consumer members chose to end their involvement in research. This may help to reflect on some of the barriers to public involvement in research and how it may be developed. Finally, I would advocate research into patients and carers who aren't involved in research, in order to understand their knowledge of the involvement agenda and reasons why some individuals do not get involved. This may be useful for addressing the apparent disparity in involved groups of patients and carers.

9.4. Methodological challenges and limitations of the study

Throughout the research I encountered a number of methodological challenges and as such have learnt that a pragmatic approach to research is incredibly important, given that the most carefully devised plans can be thrown out of kilter. In this section I will outline some of the methodological

considerations that arose from this research and the potential limitations of the study findings.

Firstly, as I have described in the methodology chapter, my original plan to conduct the research within different health research topic areas had to be altered in light of the barriers that I encountered in terms of gaining access. Whilst I feel that further research in other research topic areas would be advantageous, in terms of providing some comparisons between and across health research areas, the pragmatic decision to focus purely on the NCRN enabled me to study one network in-depth which I feel is both a strength, and a limitation of this research.

A second methodological challenge that I encountered was that during the data collection period it was apparent that the consumer participants were willing and able to dedicate more time to the interviews than the professional participants. Due to this it was far easier to develop a dialogue with the consumer members, than it was with the professional members. This is reflected in the depth and detail of the data from each group. The consumer accounts develop a much more detailed description throughout, whereas in contrast the professional interview accounts often appear slightly stilted and were clearly much shorter in length. Perhaps, this is reflective of consumer involvement in research being a passion for the majority of consumer participants that I interviewed. In addition, the majority of consumer members interviewed were retired and as such one may argue that they had more time available to take part in an interview.

In contrast, amongst the professional participants it was clear that consumer involvement in research was just a further aspect, and often a requirement, of their work. As part of this, consumer involvement did not feature highly on their agenda and clearly talking about consumer involvement in an interview was not a priority for the majority of professional participants approach. Indeed, at times I encountered some hostile responses from professional participants who appeared to consider both consumer involvement in research, and my own research aims, as trivial concerns. This was reflected in some of the interviews that I conducted and in the reactions that I encountered when observing CSG groups (for example, as described in chapter four). Furthermore, the lack of responses that I received for

professionals to take part in an interview potentially illustrates the wider attitude amongst the professional group.

Furthermore, arranging interviews with the professional participants had to be done months in advance, with last minute cancellations or 'no shows' a common occurrence. This potentially reflects the demanding nature of their careers, or again the low priority that they gave to both consumer involvement and my research. Due to this, I often had to be fairly flexible in terms of conducting interviews 'on the hop', for example interviewing one professional participant on his car phone whilst he was driving between clinical locations.

On the other hand, the difference in data depth between consumer and professional participants may reflect my own personal interviewing skills. I often felt intimidated whilst interviewing some of the professional members and in my junior status, as a new researcher with limited experience of conducting interviews, I often felt unable to prompt and probe points for further clarification. Looking through the transcripts I am able to identify areas that needed further clarification and investigation. Therefore, whilst these apparent differences between consumer and professional interview accounts suggest a potential weakness of the study, they also point to my own personal development throughout the course of the PhD.

An additional consideration should perhaps be given to the effect of the interview in prompting the consumer members to reflexively reconstruct their identities. In being asked to consider their involvement in research participants were prompted to reflect on their experiences and motivations perhaps affecting the way that they chose to 'tell the story'. Such a consideration is an inherent part of the interview method, '*a way of writing the world*' (Denzin, 2001; 25).

A further methodological challenge arose during the presentation of data. In drawing on the ethnographic tradition for depth and detail, participant and non-participant observation were a fundamental form of data collection. During the data collection period, I conducted non participant observation over the course of a year with the local research panel. Throughout this time I was developing impressions and reflecting on emerging ideas in the light of my work with the LRP. The primary difficulty that I encountered here was in

how to report these data. Personal memos and notes were not always useful to add into the findings chapters as examples of data, as their meaning may not be readily apparent to the reader. However, at the same time I was sometimes concerned that my reflections and observations could not always be supported with data, as was possible with the interview data. Therefore, explicitly referring to my observational data for the findings chapters presented a key challenge during the writing up of this thesis. Nevertheless, in accordance with the qualitative tradition it is clear that the account that is presented in this research is of course influenced and directed by my assumptions and motivations for undertaking the research (Taylor, 2002). It is intended this thesis is strengthened by the presentation of a reflexive account throughout this thesis.

Building on this, I will now turn to reflect on some further significant issues concerned with working with consumer groups and a lay advisor.

9.5. Reflexive account of the research

I end this chapter with some personal reflections about this research. In particular I will consider the process of undertaking the research with consumer groups and using the particular methodology that was chosen to explore the questions. I will also reflect on my own practice of working with a lay advisor during the course of this research.

Researching consumer groups

I began this research with a broad idea to explore the practice of public involvement in health research. My interest in this area was based on some previous research that I had conducted concerning health researchers' attitudes to involving the public in research and from my growing curiosity that developed through attending conferences in this field of research, and reading the extant literature. However, prior to beginning this research process I had a relatively limited experience of working with consumer groups. My limited experience and interest in the area had led me to believe that whilst I felt that public involvement in research could be a potentially valuable exercise, in terms of improving the feasibility and applicability of research, my limited experience of it suggested that the process was neither straightforward nor consistent.

I admit to having some rather preconceived ideas of involvement primarily formed during my time spent working in a Health and Social Care Trust where attempts were made to engage with the public at various levels. As a result my preconceptions when approaching this research included: the type of patient/carer who took part in health service decision-making and research – someone with an axe to grind; tokenistic attempts at involvement, for example I had observed lay members ignored, brought in as an 'afterthought' when professionals had been told that they 'had to involve the public', or patients/carers who used decision-making groups as an opportunity to discuss their own (or the individual's whom they were caring for) treatment and care.

Whilst recognising these preconceptions, I tried to approach the research with an open mind. And whilst the findings from this research have indicated that in some cases my preconceptions were realised, in other ways they have been tested. Certainly, in drawing on the ethnographic tradition in this research I believe that I have achieved an advantageous position of developing close working knowledge of the consumer groups, in particular the local research panel. As a result, I feel that whilst the findings have highlighted the inherently problematic and ambiguous nature of consumer involvement in health, and indicated that it may not fulfil the policy claims stated in the literature review, it does offer a unique opportunity for those involved, and consumer involvement appears to be a positive experience for the majority of consumer members involved.

What I have been most struck by during my data collection by is the strong 'commitment to the cause' that is apparent amongst the consumer members. Involvement in research for many of the members goes beyond a passing interest to something which becomes their passion. Furthermore, throughout the data collection period, the majority of consumer members that I approached appeared to be extremely accommodating in helping me collect data. Consumer members appeared to enjoy the opportunity to talk about their involvement and I feel this is reflected in the detailed interview accounts that were developed with them.

However, there were some drawbacks from working so closely with consumer groups. Firstly, I developed a loyalty to the consumer members and questioned the ethics in providing a critique of this research area. This

concern was overcome by presenting what I feel is an honest and fair account and my expectation that such critiques are vital in order to develop the practice of consumer involvement in research. Secondly, during the course of the data collection one member of the LRP sadly relapsed and died. For this particular member, their commitment to involvement in research meant that they were attending LRP meetings even when their health had reached a critical state. This experience reminded me of the social reality for many consumer members involved in research.

Working with a lay advisor

During the course of the research I have worked with a lay advisor in order to guide aspects of research. As outlined in chapter three, my lay advisor is a patient who is actively involved as a consumer member of a number of different research groups. Working with a lay advisor has been of great benefit and also, at times, a challenge. Firstly, when devising the interview schedule and questions, the lay advisor provided comments based on the practicalities of involvement (such as having an opportunity to comment on meeting agendas, when paperwork was received, the meeting location etc). From experience, he felt that these issues could provide a potential barrier to public involvement in research if they were not addressed correctly. In this way he made important contributions to the questions that I asked and my approach to the research.

Furthermore, working closely with a lay advisor was also extremely useful for testing out new and emerging ideas and discussing my interpretation of the findings. The discussions that I had with the lay advisor during this time formed part of the iterative process taken throughout this research.

Yet, I did encounter some difficulties in working with a lay advisor. Firstly, because my lay advisor also had an academic background I was able to experience firsthand the difficulties in establishing the lay role. Fundamentally, this experience highlighted how the divide between expert and lay is a superficial one and how people involved in research bring with them a whole range of additional skills and knowledge.

A further challenge that I encountered was the additional time that is needed when working with a lay advisor. Writing summaries of the research for the

lay advisor and subsequently attending meetings to discuss these took far longer than I had anticipated. Additionally, during the research process my advisor's health deteriorated and due to the nature of his illness, his mobility and communication have become progressively worse.

Finally, one of the key challenges experienced from working with a lay advisor and consumer groups is actually *ending involvement*. Developing close working relationships with the consumer groups and my lay advisor meant that it was not ethical to just stop attending meetings. In order to address this, as data collection/analysis stages drew to a close I was open with the LRP in letting them know that I would soon be ending my involvement with them and helping them to find a replacement to continue with the administrative tasks that I had undertaken for the group. Of course, I continue contact with members of the group and will be presenting findings from this research at one of their future meetings.

Although the end of the PhD marked a more defined end to my work with the lay advisor I continue to provide updates to him. It was apparent that working as a lay advisor had been a positive experience for him and in one of his emails he wrote: "*I have thoroughly enjoyed our convo's and will miss them*".

Final Reflections

In this thesis I have attempted to provide a more nuanced account of public involvement in research. The thesis has endeavoured to illustrate how what may seem to be a straightforward policy directive on paper, actually translates to a highly ambiguous and multifaceted phenomenon that extends beyond the opening up of decision-making spaces to a reflection on the very nature of credible expertise in research decision-making itself.

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Appendix A

Looking beyond the National Cancer Research Network...

1. Introduction

The purpose of this appendix is to explore some of these emerging themes outside of the NCRN. As outlined in chapter three (*Research Design and Methodology*), prior to selecting the National Cancer Research Network as the sample population for this research, some initial exploratory interviews were conducted. These interviews were carried out with professionals and the public from the Mental Health Network (MHN) and the Dementia & Neurodegenerative Disease (DeNDRoN) Network (in addition to the NCRN).

The intention of this appendix is not to produce an exhaustive analysis of the research findings from the MHN and DeNDRoN (for this is neither feasible, nor desirable within the overall aims and objectives of this thesis). Rather, the aim is to present some of the findings from the MHN and DeNDRoN that either support or contradict the findings from the NCRN (thus highlighting potential issues that may, or may not, be unique to the NCRN), and also pointing to issues that appear to be more pertinent to the MHN and/or DeNDRoN. Accordingly, it is possible to begin to reflect on the main research findings outside of the field of cancer.

Firstly, a summary of the participants who were interviewed from the MHN and DeNDRoN will be provided. Following this, the findings concerning lay roles in research, and lay and professional rationalisations for public involvement in research will be explored. As part of this, findings relating to the integration of life-world perspectives in research and the co-existence between system and life-world aims in research will be examined. Furthermore, findings relating specifically to constructions of empowerment will be presented. Finally, findings concerning the potential for lay and professional role ambiguity and the blurring of boundaries within research will be considered.

It is also important to note the terminology that will be used throughout this appendix. As mental health service users' perspectives will be explored, 'service user' is the term that will be used to describe these particular participants. For lay members from DeNDRoN the participants will be distinguished between being patients, or carers. The term 'lay' will also be used in order to distinguish between health professionals, researchers and the public.

Pseudonyms have been used throughout, and any identifying data have been removed, in order to protect participants' identity.

2. Summary of participants

Participant recruitment, the data collection methods chosen and the process of conducting the interviews are described in chapter three (*Research Design and Methodology*). Therefore, in this section I will provide a brief summary of the participant characteristics from the MHN and DeNDRoN.

Table 9.1 provides a summary of the interview participants. In total sixteen interviews were conducted with participants from the MHN and DeNDRoN. As explained in chapter three, the total number of participants interviewed within these two networks represents the total number of positive responses that were received to the invitation to take part in an interview. Only one response was received that declined the invitation to take part in an interview. This came from a professional working within the MHN who informed me that they had been advised by their departmental head not to take part in an interview.

In addition, further difficulties were experienced in recruiting mental health services to take part in an interview, in particular as I was unable to make contact with the PPI lead within the MHN. The difficulties that were experienced here are clearly reflected in the limited number of service users who were interviewed.

Table 10.1: Participant characteristics

Pseudonym	Network	Gender	Patient/service user/carer/professional
Sarah	DeNDRoN	Female	Patient
Kate	DeNDRoN	Female	Patient
Maria	Mental Health	Female	Service User
Simon	Mental Health	Male	Service User
Abigail	DeNDRoN	Female	Carer
Linda	DeNDRoN	Female	Carer
Susan	DeNDRoN	Female	Carer
Angela	DeNDRoN	Female	Professional
Margaret	DeNDRoN	Female	Professional
Elaine	DeNDRoN	Female	Professional
Richard	Mental Health	Male	Professional
Laura	DeNDRoN	Female	Professional
David	Mental Health	Male	Professional
Beverley	Mental Health	Female	Professional
Caroline	DeNDRoN	Female	Professional
Samantha	Mental Health	Female	Professional

In terms of the general demographics of the participants, all participants were of white British ethnic origin. Whilst I did not specifically ask participants to state their age, with the lay group it appeared that the majority were upwards of fifty years of age, with most of the lay participants currently in retirement from professional backgrounds. In this way, the general characteristics of the lay participants appears to reflect those found within the NCRN, and indeed those reported more widely in the literature (Martin, 2008). However, there were two exceptions to this, with the two mental health service users, Maria and Simon, both employed as service user researchers and were both aged between 20 and 40 years of age.

The next section turns to the empirical research findings and begins by reflecting on the lay participants' motivations for involvement in health research.

3. Roles and rationalisations

The research findings from the NCRN indicated that consumer roles and the rationalisation of consumers' credibility in research spaces were areas of particular complexity. Exploring, the lay roles in research and lay and professional rationalisations of the role of the public in the MHN and DeNDRoN were therefore of importance.

3.1. Lay participants' roles in research

The findings suggest that lay participants within the MHN and DeNDRoN were involved in a number of different roles. Within the MHN both of the lay participants, Simon (service user) and Maria (service user), were employed as service user researchers. As part of this, Simon and Maria were both paid researchers, involved in all aspects of the research process; including ideas generation, conducting research and disseminating findings, and they were both working within university academic departments. As service user researchers, it could be argued that Simon's and Maria's roles in research and their relationship with the academic community differed from those within the NCRN and DeNDRoN. For example, whilst lay members within the NCRN and DeNDRoN were reimbursed for their time, the employment of lay participants within academic institutions was not found in either of these networks. This potentially hints towards a unique relationship within the field of mental health between service users, professionals and the field of research.

A brief turn to the literature appears to suggest that the development of service user researchers as paid employees, and the growth of 'service user led' research, is partly a response to the ingrained power differentials between professionals and service users in mental health services (Felton et al, 2004; Turner & Beresford, 2005). In the area of mental health research, where traditionally the service user perspective has often remained unvoiced, service user led research appears to readdress the balance of power between professionals and service users (Turner & Beresford, 2005).

As part of this apparent association between the power dynamics in mental health services and service user led research, it was of little surprise that ideas concerning empowerment, personal control and feelings of value and worth were given considerable emphasis by both Simon (service user, MHN) and Maria (service user, MHN). These issues will be considered in section 3.5.

In contrast to Maria and Simon, the lay participants from DeNDRoN were involved in roles that appeared to bear greater resemblance to those in the NCRN. For example, as a lay member of a large research decision-making committee, Kate (patient, DeNDRoN), spoke of her role in "*commenting on applications for research into neurological diseases*". This consultative approach to involvement appeared to be the primary role enacted by each of the five lay participants from DeNDRoN. Such a role included commenting on the feasibility, acceptability and applicability of research protocols and in this way was similar to the roles of consumer members in the NCRN.

However, in contrast to the NCRN, which is a relatively established network, DeNDRoN is in its infancy. During an informal conversation with the PPI lead for DeNDRoN, I was informed that because of this, the structures for involving the public were also relatively new. Furthermore, it appeared that in contrast to the NCRN, where the emergence of a core consumer group was identified, such a core group did not exist within the MHN or DeNDRoN, potentially hinting towards differences in the development of lay involvement within these networks, and lay relationships with the professional groups and indeed with each other. In the light of this, lay and professional motivations for involvement in the MHN and DeNDRoN will now be explored.

3.2. Lay and professional motivations for involvement

A number of different motivations for becoming involved in research, or involving the public in research, were found within the lay and professional accounts. Firstly, there was a sense within the lay accounts that involvement in research could inaugurate change. On the one hand, some of the lay participants identified their role as advocates for research, their motivation for involvement rooted in their belief that

research could result in change, or as Linda (carer, DeNDRoN) put it: *"to find a treatment and a cure and to stop this happening to other people"*. Whilst, Abigail (carer, DeNDRoN) spoke of her 'passion for research' and clearly linked her motivation for involvement with her role in advocating for, and promoting, research:

"Well I just have this passion for research and to highlight it really and get more public support. I suppose it's only people like us that's done the caring and we know what we've been through who can really push this sort of thing forwards" (Abigail, carer, DeNDRoN).

In the extract above, Abigail provided an argument for lay credibility in research based on experiential knowledge. This will be explored in the subsequent section. In a similar way to Linda and Abigail, Kate (patient, DeNDRoN) also spoke of her motivation for involvement based on being an advocate for research:

"Interviewer: So can I ask what motivated you to become involved in research?"

Kate: I think my interest, I think we're always looking for the treatment that may help the process of the disease. It is such a fluctuating and variable disease anyway and I have a fairly benign form of it but I would still like it not to progress. I have a sort of delusion that it's not going to progress and it hasn't much in the five years since I was diagnosed"

It appeared that Kate's interest in research is driven partly through a sense of hope. In becoming involved in research, and pushing for developments in research, it seemed that Kate was psychologically invested in doing everything that she can in order to better the chances that new treatments may be found.

In contrast to Kate's motivation, Simon (service user, MHN) spoke of his motivation to 'give something back' to the wider service user group, and his sense of gratitude for the treatment that he had received. This was similar to many of the motivations suggested by the consumer members of the NCRN:

"Well I'm professionally interested in this area, as a potential career for the future. Whether or not I had experienced some of the things I have experienced I would still be interested in this research. The second and possibly more direct motivation was my own personal experiences. Finding such valuable help

with the team that I had had therapy with and finding out there was a very strong motivation to give something back..I thought if I can offer anything in terms of insight or anything like that then I'm more than happy to offer it" (Simon, service user, MHN).

In the extract above, Simon also referred to his professional interest in research as a motivating factor for involvement. Indeed, as already mentioned, Simon was employed as a service user researcher within a university. Accordingly, beyond an interest, passion or hobby, involvement in research offered the potential for career development. Similar motivations for continued involvement in research were implicit in a few of the consumer accounts from the NCRN. However, whilst Simon's status as a service user researcher, and an employee of the university, offered him some sense of structure in his career aspirations, such opportunities did not appear to exist within the NCRN.

Alternatively, two of the lay participants appeared to frame their motivation for, and subsequent role in, research in terms of fulfilling a 'watchdog' function. This role, in the words of Susan (carer, DeNDRoN) was important in ensuring that researchers "*are doing what they said they are going to be doing for the money...*". A 'watchdog' function suggests the public role in ensuring accountability in research. This finding appears to support some of the claims in the literature concerning public involvement in healthcare services and research as a mechanism to increase professional accountability and subsequently strengthen public trust in designated experts (O'Donnell & Entwistle, 2004b; Rhodes & Nocon, 1998). It was also a role that was suggested by some of the professional participants. For example, Angela (professional participant, DeNDRoN) spoke of the value of public involvement in research as keeping '*us on our toes*':

"So it keeps us on our toes in making sure that the information is accurate...I think the value is in terms of making sure that we do what we say we're going to do because I know on other projects and other organisations that it's sometimes a problem that people get money for doing one thing and then change it or don't do what they say" (Angela, professional participant, DeNDRoN).

Angela's account constructed the public in playing a regulatory role, ensuring that research funds, raised through taxpayers' money, are spent according to the approved research protocol. Furthermore, in

ensuring that professionals provide 'accurate' information, Angela also appeared to suggest that the public have a role to play in strengthening professional accountability and the transparency of research. Therefore, the public (or the life-world) govern the world of research (or the system).

In contrast, other professional participants demonstrated a keen awareness of the governance imperatives for involvement. For example, the quote by Samantha (professional participant, MHN) is illustrative of this:

"All I'm aware of is that when I try and apply for funding for research projects there's now much more emphasis on how you've involved people in this research. You have to be able to, you know, demonstrate that people have been involved at every level and how that's happened and all that kind of thing".

Samantha's recognition of the increasing requirements for public involvement in order to achieve system objectives was widely shared by the professional participants, and indeed was a fundamental motivation for the professional participants within the NCRN. Within the NCRN, MHN and DeNDRoN the professional participants were keenly aware of the necessity to comply with public involvement requirements in order to satisfy research funding bodies, research ethics committees and research governance committees. Consequently, it sometimes seemed that rather than the life-world governing the system, as argued above, the system was strategically engaging with the life-world.

Yet, it was also apparent that some of the professional participants clearly valued the involvement of patients, service users and carers in research. For instance, Beverley (professional participant, MHN) acknowledged that governance requirements provide a primary reason for involvement. However, beyond the official discourse she identified a clear value in involving service users in research:

"Erm, there are two motivations. I mean partly if I'm completely honest there are two things going on, although I think one motivation predominates over the other and I say this honestly. I think, I mean there's a pressure nowadays to do so and so on every grant application you have to outline public involvement. So there's an obligation to do it. And part of the ongoing motivation for doing it is that. But having said that I do it

because I really like doing it, I really mean this...I now do it as a matter of course, not just because it's expected but because, a) I really like working with them, they bring a completely different dimension. It's so enriching, it's so valuable in a lot of ways, partly because it makes the whole things seem so much more meaningful and relevant and purposeful..." (Beverley, professional participant, MHN).

Beverley's argument, concerning the 'pressure' and 'obligation' to involve the public, clearly parallels the findings from the professional participants' accounts within the NCRN. In chapter five, it was suggested that policy discourse may be regarded as a form of governmentality – compelling professionals to behave in a particular way. From Beverley's account, it would seem that whilst this may be the case, in fulfilling governance requirements she has encountered positive experiences and as a result suggests a role for the life-world in research. Constructing the public contribution as making research '*more meaningful and relevant and purposeful*', one may begin to reflect on a rationalisation for involvement based on the potential value of experiential knowledge. The next section will now turn to explore this in more detail.

3.3. Life-world rationalisations for involvement

In terms of the roles played by lay people in the MHN and DeNDRoN, a number of different suggestions were made. Firstly, experiential knowledge or life-world contributions were suggested. As found within the NCRN, the lay and professional participants from the MHN and DeNDRoN constructed life-world rationalisations based on the 'different perspective' that patients and carers could bring to research. For example, when asked about why she felt the public should be involved in research, Susan (carer, DeNDRoN), provided an example to highlight her construction of the 'different viewpoint':

"Susan: *I think it is finally acknowledgement that actually patients have something very worthwhile, very valid to offer. Erm, can I give you an example?*

Interviewer: *Yes do.*

Susan: *...We were invited to go to this conference and there were the people there, they have a very long name but it's really arthritis and rheumatism. And we went there to talk to them about patient participation, but in our case of course it was carer participation. But we shared the platform with two people and*

they were from the arthritis and research council. And they're doing research and it was incredibly interesting because the girl, who in a sense mirrored what I was doing – who was a patient, had the most appalling rheumatoid arthritis and she said that when she got involved the researchers all knew what they wanted to do. But when they actually went round and they asked people with rheumatoid arthritis what they would like researching there was this hugely consensus 'that we'd really like you to look at fatigue because I am so abominably tired' and no researcher had ever thought of that. And only a patient in that sense could say and I thought that was really quite insightful... And I know with my own work, which I really love actually, you often have brilliant ideas from researchers but they don't actually know what a person with dementia, say, can and can't do. You know they really don't know just quite how their money problems will affect them. And I think sometimes they need us to say 'no they won't be able to do that'.

Susan's account points to the idea of 'tacit' or 'insider knowledge' and the suggestion that experiential or subjective accounts are necessary to identify issues that are important to the public that professionals might not have considered. This construction corresponds with the claims made by INVOLVE and many of those found within the participant's accounts for involvement from the NCRN. Sarah (patient, DeNDRoN) provided a similar rationalisation for public involvement in research:

"I think again it's just providing those slightly different viewpoints. In my case from a patient/lay person perspective. Because everybody round the table has their own view coloured by whatever it is that their professional role is... So I'm looking at practical patient focussed ideas and questions that they aren't necessarily thinking of and so thinking of a different slant and making them stop and think 'well maybe that might be the way to do things, or not'.

(Sarah, patient, DeNDRoN)

It appeared that within Sarah's account there were two key elements; firstly the idea of 'tacit' or insider knowledge, enabling the public to identify areas for research that may not be on the professional radar. Secondly there was a sense that some the public could be indifferent to any institutional or funding priorities that researchers and clinicians might be subject to. In other words, a suggestion that lay people can provide a dispassionate or even-handed assessment of research because they were effectively 'outside' of organisations funding and undertaking research. In this way, the argument for the 'different perspective' is compliant with the 'extra scientific' model for involvement as proposed

by Dyer (2004), with the public providing value assessments of research. This idea was also shown in the quotation by Linda (carer, DeNDRoN) when she was asked about the benefits of involving patients and carers in research:

"And also I think we are truly independent. My only purpose in doing this is to try and find some answers. I do not have a PhD at stake, I do not have a career at stake ... and therefore you are sitting totally outside of that process and can, and can just assist" (Linda, carer, DeNDRoN).

However, when pressed on what she meant by this, in particular what the phrase *'find some answers'* meant in practice, there appeared to be no added specificity above and beyond those issues already raised (for example, a role commenting on patient recruitment and information about clinical trials).

In a similar way to the lay participants from the MHN and DeNDRoN, some professional participants' rationalised public involvement in research based on the lay role in providing a 'reality check' to research. The quote by Richard (professional participant, MHN) highlights the various aspects to this argument:

"I suppose we want to have a viewpoint which is not a professional viewpoint. Erm, I think it's also sometimes useful, you know, when we are thinking about approaching people and discussing how to carry out the trial, you know, those are pretty sensitive people. I think it is good practice to have somebody who perhaps doesn't identify as strongly with the research, getting research done. You can say 'hang on a minute, that's not a very good idea' or make some comments along those sort of lines. But erm, but that's what we're interested in, is the slightly different perspective and then we've got somebody who can make a better guess than is about what people may think about various bits of our research".

Richard's quote suggests the lay role in bringing a viewpoint that is different to that of the professionals, although in what ways this may be different is not expanding on. Additionally, Richard appeared to identify the role of the public in bringing a perspective that is 'outside' of the systems imperative of research, *'somebody who perhaps doesn't identify as stringing with the research, getting research done'*. This corresponds with the constructions provided by Linda (carer, DeNDRoN) and Sarah (patient, DeNDRoN) discussed above. Finally, the 'different viewpoint',

as constructed by Richard, suggests the lay role in providing a voice for the public and, whilst not implicitly stated, is suggestive of the lay role in bringing the voice of the 'life-world'.

Certainly, within the interview accounts of the professional participants from the MHN, there appeared to be a strong sense of support for service user involvement in research. This appeared to be attributable to a recognition of the necessity for subjectivity in mental health research, thereby legitimising the role of their life-world. For example, David (professional participant, MHN) reflected on this:

"I think as an aim it's a really good one. Certainly in the mental health field but probably elsewhere. But mental health is what I do. I think it might be more important in mental health than other areas because mental health is probably an area that has greater discrepancy amongst professional opinion. So for example if you break your leg, everybody tends to agree that you've broken your leg and what you need to do to get it better. And in mental health it's not that clear because people don't agree on what's wrong with somebody. Even if everybody agrees that somebody's depressed there might be 6 different ways of understanding that, it might be a biological disease, it might be a response to life event, it might be to do with your upbringing, it might be to do with all sorts of things. Professionals tend to not agree with each other and therefore the view of the person experiencing it themselves is probably more important when there's a range of options and the professionals can't agree".

David's account seemed to be suggestive of the centrality of the life-world to understanding psychological conditions. Without an appreciation of life-world perspectives, one is unable to understand the metaphysical. This idea corresponds with an argument proposed by Barry et al (2001). In their work on the use of communicative and strategic action in the clinical consultation, Barry et al (2001) found that communicative rationality and reference to the life-world was most prevalent in relation to consultations for psychological conditions. Barry et al (2001; 500) argue that one reason for this may be that:

"Psychological conditions are more rooted in the lifeworld ... psychological conditions are defined by, and success of treatment is measured by lifeworld terms of reference".

This explanation clearly resonates with David's (professional participant, MHN) rationalisation for service user involvement in research.

Yet whilst the experiential knowledge, or the 'different viewpoint', of the public was often suggested as a primary rationalisation for involvement, it was apparent that other issues around credibility and lay status were still problematic within the MHN and DeNDRoN. These issues will now be explored.

3.4. The supremacy of technical knowledge

A key finding within the lay members' accounts was a clear sense of deference towards certified forms of knowledge. Again, this appears to resonate with accounts from consumer members in the NCRN. For example, lay participants in the MHN and DeNDRoN appeared to align themselves as working with the professionals, constructing collaborative relationships and alliances rather than antagonistic connections. For example, Maria (service user, MHN) spoke of the complementary nature of service user and professional roles. Maria's account is illustrative of the accounts from the wider sample of lay participants from the MHN, DeNDRoN and NCRN:

"Because I don't think we could do what we're doing in the way that we are without all those different perspectives there. Without professional researchers we would seriously struggle. Without the clinicians we wouldn't understand some of the clinical meanings behind some of the conversations we've got to transcribe. And without the users and carers you wouldn't get that really personal perspective of how it feels" (Maria, service user, MHN).

Within Maria's account the boundaries between the service user role and the professional role appear to be relatively clear-cut, with the professional associated with technical knowledge and the service user identified with experiential knowledge. From this, one may assume that the tension and 'grey area', with regards to the positioning of lay participants in research in terms of being recognised as a credible voice, that is evident within the NCRN does not appear to be an issue within the MHN and DeNDRoN.

Indeed, in contrast to a general movement with the NCRN, whereby consumer members were identified to be increasingly involved in forms

of technical training, none of the lay participants from DeNDRoN spoke of undertaking any specific training or the necessity to converse in the techno-scientific discourse, and the service users from the MHN were provided with training as part of their employment. However, whilst the specific tension identified between experiential and certified forms of knowledge that was highlighted within the NCRN might not apply to the MHN and DeNDRoN, it was apparent that certified forms of knowledge were often associated with greater legitimacy and credibility in research. This was particularly evident when Simon (service user, MHN) spoke of his desire to achieve the same certified expert position afforded to the professional members of the research group. It appeared that Simon associated certified expertise with enhanced credibility and legitimacy in research:

"They're all in their positions because they have attained certain levels of academic or professional achievement that I haven't achieved yet and I'm only really in this position because of my service user status. So I'd much rather think I'm capable of being in their positions on my own merit."

It could be contended that Simon's aspiration to achieve certified status may be partly attributable to working in mental health research. As illustrated in section 3.5, discourses of empowerment, specifically feelings of value and self worth, appear to be extremely poignant within the service user accounts from the MHN. In achieving certification, Simon (service user, MHN) would have 'proof', or validation, of his right to be involved in research.

More widely, it seemed that a couple of the lay participants felt a sense of discord with the 'lay' label and identity. Many of the lay participants felt very strongly that the other aspects of their identity, over and above their patient, carer or service user status should be recognised, with a particular focus on lay participants' careers, skills or training. For instance, in the quotation below, Sarah (patient, DeNDRoN) reflected on the 'patient' label and the status that she associated with this label:

"Everybody's titles are put down but there's a great tendency to put you as a second class citizen and just put, you know you'll have Professor so and so and Dr. this and Sir that, and then you'll have patient [name removed]. And I have fought that. So I think there is still a tendency for the lay representatives to be a lesser mortal and I

don't mean within the small context of the people that I'm working with doing the study group. But within the administration for the big organisations which are organising training days or conferences, I've done various speeches at various things, and that I've found has happened several times and I have protested about it".

It would seem that in discounting Sarah's title, her sense of legitimacy is undermined. In referring to lay representatives as 'lesser mortals', the significance appears to be that certified professionals are granted greater credibility than patient or public members.

Furthermore, in rationalising her involvement in research, Sarah was quick to provide her certified credentials:

"Well, I suppose I'm involved really as a lay representative on several groups. And my background is medicine and because of ill health I retired I couple of years ago. So I've obviously got some expertise in medical research anyway, although I wasn't an academic as such, erm a practising clinician, I did do a bit of research and obviously had a reasonable understanding of research methods and obviously the, sort of cellular biology behind it... I think probably the feeling that with the background that I've got I've got an understanding of what goes on and it would be nice to be able to contribute to, I suppose not just to research, but in a public capacity to the various organisations that actually need somebody to be on their panels. And I think having that knowledge helps me to understand contribute in a, I hope, positive manner" (Sarah, patient, DeNDRoN).

Likewise, when asked about her interest in research, Kate (patient, DeNDRoN) explained, *"I'm a retired GP and I've got Parkinson's disease"*. What is implicit within these rationalisations for involvement is the centrality of Kate's and Sarah's clinical knowledge. Indeed, Kate went on to express her surprise that other lay participants involved in research were not qualified with the same levels of certified knowledge:

"I was surprised first of all that it should happen and as a GP I thought 'oh well what have they got to contribute?' And I felt that when they were asking me it wasn't as the public but perhaps I can contribute more as a doctor" (Kate, patient, DeNDRoN).

Clearly, Kate identified her legitimacy in research based on her certified knowledge, or her potential to draw on her 'referred expertise' (Collins and Evans, 2002). It is unclear whether Kate was asked by the wider professional group to be part of a research group owing to her clinical background, or whether this was Kate's own perception of her role.

However, it does appear that Kate locates her credibility for involvement in research within her clinical certification. Such an account is perhaps comparable to the scientifically engaged model of involvement that was identified within the NCRN, suggesting certification and the ability to converse in the techno/scientific discourse as directly related to lay participants' credibility in research.

Therefore, having so far reflected on the findings related to lay and professional motivations and rationalisations for involvement and the roles that lay participants play in research, attention will be given to one key benefit associated with involvement – empowerment. Empowerment and personal control are often cited in the literature as fundamental to public involvement in research¹. Furthermore, it has already been highlighted how these issues were identified as key themes within the consumer members' accounts for involvement from the NCRN.

4. Empowerment and control

As outlined above, issues around empowerment and control were of apparent significance to Maria (service user, MHN) and Simon (service user, MHN). As previously mentioned, discourses of empowerment seem to have greater significance within mental health services, owing to the controversial history of psychiatric care and the rise of the anti-psychiatry movement (Felton et al, 2004). Within Simon's and Maria's accounts, one of the greatest senses of empowerment appeared to be an association with feeling valued. Ultimately, it appeared that for Maria and Simon, involvement in research reflected a complete change in the power dynamic between professionals, or providers of health services and service users as receivers of health services. For example, the extract below taken from the interview with Maria is clearly illustrative of this:

Interviewer: *Is there anything else that you'd like to add about your experience of being involved in research?*

Maria: *I'd just really recommend it to service users and carers, I really would. It's an empowering experience because you're in a different position, you're not somebody receiving, you're actually*

¹ For example, INVOLVE claim that involvement in research "can help empower people who use services" (Hanley et al, 2004)

enquiring. So it's a totally different role. You go into a unit as a researcher rather than a patient or a relative. You are in a very different position. The staff are nervous of you! I do think people should just do this. I would really recommend it because it puts you in a different role. It's a great experience. And I've learnt so much from it and met so many interesting people as well" (Maria, service user, MHN).

From this, it would seem that Maria constructed her involvement in research as a positive experience. She emphasised the difference in the way that professional members of staff responded to her when she embodied the role of the researcher, rather than that of the service user. It is apparent that Maria equates her role as a researcher in a more active manner - the 'enquirer' - and as such states feelings of empowerment from being able to play an active role.

Building on this, it appeared that Simon (service user, MHN) constructed the service user researcher role as an essentially privileged position. He acknowledged the 'short cut' that such a position had given him into the world of research:

"It's very often I feel valued and appreciated and it's an amazing boost. Because I think I have what I might call normal colleagues, assistants in various parts of the building who might be assistant psychologists with a good few years experience or even therapists who have quite serious qualifications, they might not for a number of years have the opportunity to sit on committee with those kind of people or to be offered the kind of opportunities that I find that I am. So I feel there's empowerment in that service users are often given, not for no reason, a short cut to instant access to occasionally the higher levels of our professions. Which is very very empowering. This kind of direct route, which somebody coming through a kind of normal career path could take them a much longer time to have a personal opinion heard or have a particular preference heard whereas service users been given this opportunity, having these doors opened are finding, on a personal level finding themselves been taken seriously" (Simon, service user, MHN).

It appeared that Simon associated "having doors opened" into academic research and being taken seriously, due to his role as a service user researcher, with a sense of credibility and legitimacy in the service user voice. The opportunities that Simon described, as a result of his service user researcher status, are clearly experienced as empowering.

In contrast to the accounts of empowerment suggested by Simon and Maria, which appear to be associated with their relationship with services, two of the lay participants' from DeNDRoN, spoke about involvement in research in terms of a mechanism to maintain, or rebuild, particular aspects of their lives. Nowhere was this more clearly demonstrated than in Linda's (carer, DeNDRoN) emotive account of the impact that caring for her husband had on her life:

"So it's a nightmare existence that we have. Not only did he lose his career but I lost mine. And I went from full time work to part time work and I had young children and I was desperately trying to keep this family together. And when I'd have to support him I then went to no work. And then I'd go back to part time work because it looked as though we were on a steady patch and then I'd have to stop that after a year of so. You're living on a roller coaster. So you've basically ended up losing everything ... And he couldn't be left alone. You could only do work where people knew your situation and that you'd get it done. So yes, you become very very isolated as a carer and this does allow you to keep contact with the sort of level of professionals, certainly in my case, that I was used to working with. And also work in a professional capacity, even though we're not being paid for it. And also when you come out of this, because there is only one result when you get this diagnosis and that is death, you're still sort of hanging in there when that happens, if you know what I mean? Otherwise you could be totally isolated in your house because you lose all your friends, you lose all your social contacts when you are suffering from this disease."

(Linda, carer, DeNDRoN)

What is particularly interesting within Linda's account is that she provided a carer's perspective. Whilst consumer accounts for involvement in the NCRN indicated a sense of 'biographical disruption' pointing to the impact of cancer on consumers personal, social and working lives, these accounts were primarily from a patient's perspective. In the example provided by Linda, we are able to reflect on the possibility of 'biographical disruption' through a carer lens. In Linda's own words, her experience of caring for her husband resulted in her '*losing everything*'. Her relationship with her husband was fundamentally altered, family life was affected and her career was ended resulting in feelings of isolation and a loss of social contacts. Effectively, involvement in research appears to have provided Linda with a 'lifeline', enabling her to work 'in a professional capacity', ensuring some form of social network and preserving elements of her former, 'pre-carer' self.

This is a powerful construction of the potential empowering affects lay participants can experience as a result of being involved in research.

However, whilst the lay participants suggested seemingly positive constructions of empowerment, it was also apparent that public involvement in research could result in some potentially disempowering experiences. These will now be explored.

5. Blurring boundaries

Whilst the positive aspects of involvement and collaborative working practices have been identified above, the findings also alluded to some potentially problematical issues. Of particular note here were the findings concerned with the potential for the 'blurring of boundaries' between the roles of the public and the roles of professionals in research.

Firstly, within the MHN, it appeared that whilst working as a service user researcher had empowering effects, it could also present an emotional challenge for service users. For example, whilst Maria (service user, MHN) spoke of being empowered through involvement, clearly associating this with a change in the power dynamics between the professional and service (as discussed above), on occasion her service user status was reinforced. In particular, Maria recounted an incident when involvement in research had an emotional impact with severe consequences. In the extract below, Maria can be seen reflecting on this. She begins by explaining how she had been involved in analysing interview transcripts as part of her role as a service user researcher:

"We're all involved in analysis, anybody who wants to be is involved in analysis. There have been lots of issues about that because we're all involved but for people who are using services and caring for people the content of some of the meetings was actually, it was quite difficult even for the professionals to read apparently... One of the transcripts we did a couple of months ago was very similar in content to my own issues and I had major problems with that so it was about self harm and suicidal attempts and the lady doing it was actually using overdosing which was the method I actually used myself. There were lots of issues it brought to the front for me...Well it was totally unexpected because of course the researcher had done this but we hadn't actually seen the transcripts. So what happened was the researcher sent them out by post to us and we actually read

them on our own. (laughs) This particular case for example you got the service users view, you got the care co-ordinators views and there was also the transcript of the entire meeting and the observations of the researcher as well, so there was a lot of data on it anyway but it was all quite intense and the person was obviously not very well at all at the time. So yes so I was reading it at home on my own actually! So that had an issue in that it led to me overdosing” (Maria, service user, MHN).

Maria’s account highlights one extreme example of the possible emotional impact that research can have on lay participants. Whilst Maria was involved in research in a professional capacity, it appeared to be difficult to distinguish between using her subjective, experiential knowledge in a constructive way with the potential for this knowledge to have destructive consequences.

A second way in which the blurring of boundaries was identified as problematic was in the ‘professional-as-colleague’ versus the ‘professional-as-practitioner’ roles. For example, David (professional participant, MHN) found himself employing a practitioner role advocating for service users with whom he also worked with in a professional (colleague) capacity:

“I guess for me, personally the biggest difficulties have been when people have become unwell. Because of my clinical knowledge I feel equipped with skills to improve the situation and because of the rubbishness of the routine NHS services where they happen to live, they’re not provided with those things by other people. And therefore I’ve got involved in advocating for people at ward rounds, trying to arrange psychological therapy for people. I’ve not actually yet embarked on trying to deliver psychological therapy personally to one of them because that would feel to be inappropriate really, erm, but I can see me being tempted! But I guess I’m in a position where I can facilitate other people seeing them. But it has been really problematic in the past. And has landed myself and colleagues in trouble as well because we have been deemed to be overstepping our boundaries as it were...” (David, professional participant, MHN).

In this way, it appeared that David adopted a dual identity based on his role as a practitioner and that of a co-researcher, with an apparent ‘grey area’ between the two. In a similar way, Elaine (professional participant, MHN) identified the potential for lay participants to engage with professional researchers in order to elicit their professional expertise:

"I think there's a great danger if you work with a very small group of people that inevitably we all have our axe to grind and that came across very clearly...I listened a lot to what they had to say and then tried to move on. Because some of the things they were telling me were horrific. But they were about, one lady was about her husband and care and you had to switch back to being a nurse and listen, empathise and then move on. Because I couldn't, her stories were so sad, but it wasn't anything to do with my research. And that sounds quite hard but it's not meant to" (Elaine, professional participant, MHN).

Therefore, as illustrated above professional participants 'hybrid positions' appeared to be negotiated, with professional participants reflecting on when to draw on their certified expertise and in what context. This often signalled a potential dilemma in distinguishing the doctor/patient relationship from that of the worker/co-worker.

6. Summary

In this appendix, I have provided a brief account of some of the findings from the initial exploratory interviews conducted within the MHN and DeNDRoN. The purpose of this appendix was to present findings that would support, or directly contradict, those identified within the NCRN. As such, it was intended that one may begin to reflect on the themes and arguments related to the NCRN within a wider context, i.e. public involvement in health research more broadly.

The findings presented indicate that within the NCRN, MHN and DeNDRoN slightly different approaches to involvement in health research have been taken. The MHN appears to place a greater emphasis on service user led forms of research, with service users working as paid researchers. In contrast, lay participants within DeNDRoN and the NCRN are more likely to be involved in collaborative processes, providing advice to professionally led projects.

It is apparent that similar motivations for involvement can be identified between the lay and professional participants from MHN, DeNDRoN and the NCRN. However, in contrast to the MHN and DeNDRoN, within the NCRN a greater sense of a core consumer movement was identified. As part of this, it was argued that the development of a collective identity often served to encourage consumers to become and remain involved in

the NCRN. The existence of similar collective groups within the MHN and DeNDRoN were not ascertained. This may be because such collective groups do not exist within these networks, or it could be that further research is needed within the MHN and DeNDRoN in order to further explore this.

The findings from the MHN and DeNDRoN also highlight that similar issues exist concerning system/life-world tensions in research, and the privileging of certified forms of knowledge. Consequently, it was apparent that there was some ambiguity over lay participants' roles in research with the potential that rationalisations for involvement may also be based on the extra scientific and the scientifically engaged models for participation, as suggested within the NCRN.

The findings suggest that within the MHN in particular, issues of empowerment and personal control are central to service users' involvement in research. It appeared that these issues have greater significance with the MHN than the other networks, perhaps owing to the inherent power dynamics between service users and professionals within mental health service provision.

Finally, it was suggested that the potential for the blurring of boundaries, between professional/patient, colleague/co-worker, service user/researcher, was apparent. This is of particular relevance within the MHN, where service users' life-world experiences are based on their psychological conditions. As a result it appears that the emotional impact of involvement may be more complex for lay participants in mental health research than perhaps in other fields of research. Such blurring of boundaries also affected professional participants' roles and relationships with lay participants in research. Again, this is seemingly more complex in the MHN, potentially indicating a unique relationship between system and life-world in mental health research. Further research is necessary to begin to reflect on this in any meaningful way.

Appendix B

Interview Questions

1. To start off perhaps you could tell me about your opinions towards public involvement in research? Is there anything in particular that you would like to raise?
2. Perhaps you could tell me a little about how, when and why you came to involve the public in your research/panel. / How you came to be involved in research?
Prompt: what was your motivation?
3. Involving the public in research is encouraged in government policy. What is your understanding of this policy?
Prompt: why does it feature in government policy at all?
Significance in terms of how things were before?
4. How do you feel about the aims and objectives of this policy and its practicality?
5. Thinking about your experiences of public involvement again, who have you recruited and why? / who is recruited and why? (breadth of people)
6. How do you recruit people? How were you recruited?
Prompt: How people are approached, encouraged, discouraged, filtered? Was recruitment straightforward? Are the right incentives in place?
7. How long are people involved for? How long have you been involved?
8. Do any groups/bodies/individuals influence your decision to involve the public in research/ be involved in research? If so, what are your feelings on this?
9. RESEARCHER ONLY – Do you think that involving the public in research helps or hinders you in your work? Explain. Some people think that by increasing the role of the public in health care research this reduces the role of the professional, what are your views on this?
10. PUBLIC ONLY – How do you think your involvement in the research/panel has benefited/dis-benefited you/ the patient group that you represent?
11. In terms of how the research team/panel functions what role do the public play? / What role do you play? How is this role different to other panel/tem members?
12. How was the public role defined and negotiated? Was the role made explicit in meaning? How (if at all) is the role facilitated by the principle investigator/chair?

13. How would you define 'successful' involvement of the public in research? What factors maximise success? Has this been your experience? Explain & examples.
14. What types of activities are the public/you involved in? How do you prepare the public for this?/ How were you prepared for this? Was the preparation adequate?
Prompt: were the public/ you helped to understand jargon?
Listened to?
15. How do you feel that the group works together?
Prompt: public voice taken into consideration?, who sets the agenda? How are groups facilitated?, were introductions made?
High and low points?
16. To what extent do you think the public/ you can contribute towards research?
17. What have the public brought to the research?/ What have you brought to the research? What have the group gained? Is this different to what you initially imagined?
18. Researcher - Are there any special/unique challenges from working with X group? – How do you address these?
19. Public – How are the challenges of you being involved taken into account? (paperwork, distractions, advance notice, seating, lighting, day or night meetings, access).
20. Overall, what impact do you think involving the public has had on the research?/ do you think you have had on the research?
Examples.
21. With the benefit of hindsight what, if anything, would you do differently?
22. Is there anything else that you would like to add about public involvement in research based on policy, theory or your own experience?

Appendix C



School Of Health
and Related Research

Version 4. 8th October 2007

**DIRECTOR OF PUBLIC HEALTH
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Participant Information Sheet

Title of the project: **Exploring the relationships between the public and professionals in the health research process**

Invitation to take part in a Case Study

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully.

What is the purpose of the study?

This research is being undertaken as part of a larger PhD project looking at the relationships between the public and professionals in the health research process. Specifically how professionals and members of the public work together in a research capacity and how they feel about their role in research.

Why have I been invited to take part?

The clinical study group that you attend has been identified as a potential case study for the research because it provides an example of the public and professionals working together in a research capacity.

Do I have to take part?

It is up to you to decide. Once you have read this information sheet we will ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason.

What will happen to me if I take part?

If you decide to take part, once we have received a consent form from each member of the group we will arrange to attend some of the group meetings. The researcher will observe the meetings and may make some notes during these meetings. The presence of the researcher should not interfere with the normal meeting procedure that you expect.

The researcher will also contact you to ask if you would like to take part in an interview. If you agree to this a time and date that is suitable for you will be arranged. The interview will be semi structured, allowing flexibility for you to discuss matters that you think are particularly interesting or important with regards to your role in the group.

What will happen to the results of the research study?

Notes from the observational work will be written up and store in a lockable office.

The interview will be tape recorded and the recorded data will be transcribed and analysed by the researcher. The transcribed data will be stored on a password protected computer and the audio data will be stored in a lockable cupboard. The data will be destroyed 5 years after the study has been completed.

The data from the transcripts and the observation notes will be used in the researcher's PhD thesis and any subsequent publications. All data will be anonymised to protect your privacy and no individual participant will be identified in any way from the published material.

Will my taking part in this study be kept confidential?

All information collected during this study will be anonymised: your individual responses will only be seen by the researcher and her educational supervisors, and not by any other participants or by our advisors. Opinions or views that you give will not be attributed to you in any reports that result from this research.

What are the possible benefits of taking part?

There will be no direct benefits to you. The opinions that you give during the research may lead to a better understanding of the realities of public involvement in research.

What if something goes wrong?

There is no reason to think that taking part in this study will lead to any harm to you. There are no special compensation arrangements. In the unlikely event that you think taking part in this research project caused you harm, please contact: Cindy Cooper, Senior Research Fellow The University of Sheffield, School of Health and Related Research, Regents Court, 30 Regents Street, Sheffield, S1 4DA, phone 0114 222 0743 to express your concerns. Should you feel that your complaint has not been handled to your satisfaction, please contact Dr David Fletcher, The University of Sheffield Registrar and Secretary, phone 0114 222 1101.

Who is organising and funding the research?

This research forms part of a PhD research project undertaken in the department of Public Health at the School of Health and Related Research, The University of Sheffield.

The PhD student has received a studentship from the Economic and Social Research Council and some additional funding has been given by the Sheffield Health and Social Research Consortium.

Who has reviewed the study?

This study has been reviewed and given favourable opinion by Leeds West Research Ethics Committee

Further information and contact details

Jill Thompson

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Appendix D



School Of Health and Related Research

Version 4. 8th October 2007

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CONSENT FORM

Title of Project: Exploring the relationships between the public and professionals in the research process

Name of Researcher: Jill Thompson

I confirm that I have read and understand the information sheet dated 8th October 2007 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.

I agree to take part in the above study and understand that the data collected may be used as part of a PhD thesis and subsequent publications.

Name of Participant..... Date.....
Signature.....

Name of Researcher..... Date.....
Signature.....

Appendix E

NATIONAL CANCER RESEARCH INSTITUTE (NCRI)

CLINICAL STUDIES GROUPS

NCRI [name removed] Clinical Studies Group

Meeting to be held from 13.00 until approximately 16.00 on XXX 2008 at CRUK, in Room XXX, London.

AGENDA

- 1. Chairman's Business**
- 2. Notification of items of any other business**
- 3. Minutes of the previous meeting**
- 4. Matters arising**
 - 4.1. Update on action points**
 - 4.2. Report from XXX** **Verbal**
 - 4.3. Other matters arising not on the agenda** **Verbal**
- 5. Updates on UKCRN, NCRI, NCRN, NHSC and NICE/HTA**
 - 5.1. UKCRN** **Verbal**
 - 5.2. NCRI** **NEWSLETTER**
 - 5.2.1. Consultation on access to samples for research**
 - 5.2.2. National Awareness and Early Diagnosis Initiative**
 - 5.3. NCIN** **Verbal**
 - 5.4. NCRN**
 - 5.4.1. Attendance at last 3 meetings**
 - 5.4.2. Report from Chairs Forum** **Verbal**
 - 5.4.3. Industry Trials** **Verbal**
 - 5.4.4. Report back from XXX** **Verbal**
 - 5.4.5. Update on CSDGs**
 - 5.4.6. Report from Project Officer**
 - 5.4.7. Annual Report**
 - 5.4.8. Action plan from Progress Review : Proposal to revise subgroups** **Verbal**
 - 5.5. NHSC**
 - 5.6. NICE/HTA** **Verbal**
- 6. Report from Consumer Representative** **Verbal**
- 7. Trials Portfolio**
 - 7.1. Accrual to XXX trials in the NCRN Portfolio**
 - 7.2. Reports on ongoing trials and trials in set-up**
 - 7.2.1. Progress of trials in the portfolio** **Verbal**
- 8. Trials in development – Reports from Subgroups Chairs**
- 9. Trials submitted for funding**
- 10. AOB** **Verbal**
- 11. Date and Time of Next Two Meetings**

Appendix F: Job description

Job description: Local Research Panel Member

Post	Local Research Panel Member
Duration	The usual term of office is 3 years
Payment	Payment will be made for attendance at meetings or consumer input into research projects based on £7 per hour. Travel expenses and other out of pocket expenses will also be covered

Background

A consumer is someone who uses a service. The service is in this case the NHS and its consumers are patients (or potential patients), carers, long term users of services, organisations that represent these people's interests, and other groups affected by the service they receive from the NHS. They come from all sections of the population.

Among many health care professionals working within XX there is a growing recognition of the value of consumer involvement within the area of cancer care. Furthermore, there is increasing awareness of the obligation for research studies to include input from consumers at all stages. It has been stated that consumer involvement should not be seen as a parallel development to the Cancer Networks but be fully integrated into structures at the national, regional and local levels.

Involving consumers in research can result in a number of key benefits – improving the quality, choice and relevance of services and technologies available.

However, obtaining input from consumers can be a problematic and time-consuming process. There are issues such as recruitment,

representativeness, expertise, training and continuity of input that need to be addressed. Involving consumers in the past has been on an ad hoc basis that has meant that the consumer's role has inevitably been diluted. In order to try to overcome these difficulties we have established a Local Panel for Research. The Panel consists of people who have experience of cancer, as patients or carers, and who are interested in research.

Principal responsibilities

- 1) To attend the training programme for members.
- 2) To attend a number of Panel meetings a year. Four Panel meetings are held every year. These are in addition to the individual project meetings attended. They are an opportunity to meet fellow panel members and keep abreast of current developments. We understand that sometimes people may be unable to attend all these meetings.
- 3) To deal with the associated paperwork of the Panel. Members may be required to read certain paperwork before meetings.
- 4) To attend project meetings (as negotiated). Members will be required to contribute to the discussion to ensure that consumer priorities, rather than individual priorities, are reflected, and to ensure that the final decisions take into account issues of concern to consumers overall.
- 5) To have a mentor (if required). All new panel members will be offered a mentor, who may be either a member of staff or an experienced panel member. Experienced consumer panel members may be asked to act as a mentor in the future. The mentor will:
 - welcome members at the first meeting
 - answer any questions personally answered in confidence at the panel or project meeting

- provide guidance and support on issues around activities relating to the panel
- 6) To declare any conflict of interest. Panel members are requested to declare any conflict of interest. For example, a study may be discussed where a member of the research team may also be a consultant personally known to the member.

Factor	Essential Attributes	Desirable attitudes
Qualifications	None	None
Experience	Former or current cancer patient or carer	Committee experience Links with consumer networks/associations/society
Special Skills	Willingness to familiarise yourself with medical and research language	To keep up to date with current research issues
Specialist knowledge	Knowledge of consumer perspectives	To have an understanding of research
Personal qualities	Good communicator Ability to listen to others and express own views about consumer concerns in discussions	Self confidence in a mixed group of professionals and consumer advocates Able to respond to challenging tasks Experience of receiving fairly complex agenda papers and preparing for meetings

Terms of reference

1. Introduction

These terms of reference outline the operations of the Panel, Executive Committee and the Associate membership, and their interactions with professionals and departments. They are meant as a guide, for the effectiveness of the three groupings, to ensure that they remain within their remit, and to enable them to liaise with professionals and others smoothly. The main aim of the LRP is to increase the engagement of consumers of cancer care in the whole research process – from generation of research questions, through protocol development and advice on issues such as ethics and patient recruitment, to actual consumer participation as researchers, presenters and co-authors of peer-reviewed papers.

In this document there is reference to the Local Panel, Executive Committee and Associate Membership

- The Panel consists of all individuals who are registered as members through the Facilitator. The panel membership is set at a maximum of 30 at any one time and is additionally supported by the Associate membership.
- The Associate membership consists of members of the panel who for various reasons are not able to attend the regular panel meetings but wish to be associated with the work of the panel and contribute on a more occasional basis. Associate members receive panel meeting notes and other relevant documentation to enable them to remain fully informed and participate by either email or by post.
- The Executive Committee consists of a sub group from the panel, and includes the LRP Chair, the LRP Vice Chair, the AUSC Head of Department, the LRP Facilitator and the LRP Project Secretary. The Executive Committee will be responsible

for overseeing the LRP subgroups such as the website, newsletter, research and conference planning groups.

2. Structure

- 2.1 The panel will consist of 30 members at a maximum, and will meet at the panel business meetings quarterly (or more frequently if necessary). The key functions of the panel will include some (or all) of the following; to be the consumer voice in the development, monitoring and evaluation of cancer research projects both local and national; to act as an advisory body to professionals wishing to produce research proposals for areas of cancer research; to act as an advisory body to cancer, supportive and palliative care clinicians/researchers seeking to educate service users and the general public about cancer care issues.
- 2.2 New members will be provided with appropriate training opportunities to enable them to formally participate in the activities of the panel in agreement with the Executive Committee.
- 2.3 Formal decision-making will only be possible when there is a quorum of the Panel at one of the quarterly panel business meetings. That quorum will be two-thirds attendance (this will not include the facilitator – a professional officer of the Executive Committee).
- 2.4 Officers of the Executive Committee will be the Chair, Vice Chair and Facilitator.
- 2.5 The Chair and Vice Chair posts will be elected by LRP members, for a period of two years, with the option of a further term (2 years) if it is the wish of members.
- 2.6 Key responsibilities of the Chair and Vice Chair will be to attend Executive Committee meetings, to manage the agenda of panel meetings giving priority and timings to matters for discussion; to lead the panel discussions and to facilitate

decision-making, ensuring that appropriate levels of agreement are determined and recorded; to represent the views and decisions of the panel in other forums, in particular at local strategy meetings. To liaise with the panel membership and the University department in all aspects of the LRP sub groups.

2.7 The Project Secretary will be responsible for the minutes of meetings and their dissemination in a timely fashion and circulation of any documentation or presentational matter pertinent to meetings as well as the day to day administration of panel business in collaboration with the LRP Facilitator.

2.8 The Facilitator will be a professional member of the University. This will ensure effective liaison between the Executive Committee and the University, and will have the advantage of offering professional advice and support to the LRP.

3. Meetings Venue

Meetings will be held at the XXX, unless otherwise stated on the agenda. Other venues may be required if the Committee are meeting cancer site-specific multidisciplinary teams, or other patient groups.

4. Financial Management

The committee will have no direct responsibility for the funds allocated to its functioning as a project. However, a financial statement should be offered by the Facilitator at each panel business meeting.

Claiming expenses: Members of the panel are entitled to claim a panel fee plus travel expenses for attending LRP meetings or other LRP related activities. It is the individual's responsibility to enquire to their own personal tax/benefits office about the effects of any such claims on their own personal financial circumstances such as sickness and unemployment benefits etc.