

# WHAT IS GOING ON IN PUBLIC INVOLVEMENT IN HEALTH RESEARCH?

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A QUALITATIVE EXPLORATION OF AIMS, PROCESSES  
AND OUTCOMES

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## **Abstract**

This project aimed to understand what was going on in public involvement in health research based on an investigation of the relationship between the practice of involvement and conceptualisations of involvement in the literature. A qualitative exploration was conducted of two case studies where researchers involved members of the public in the design, planning and conduct of health research. The methodological approach drew on realism, reflexivity and abduction. Data were gathered by observation, interview and collection of documents.

The literature review identified that key critiques of involvement practice were based on different understandings of the purpose of involvement, and that normative and substantive rationales valued different kinds of outcomes with significant implications for both the conceptualisation and evaluation of involvement. Key components of involvement were distilled from the literature and not all were addressed by current conceptualisations of involvement in research. Findings suggest that the evaluation of involvement practice based on rationale and key components has potential to improve understanding because the criteria for judging practice are closely related to desired outcomes and address all aspects of involvement agreed as important.

The case studies provide a rich picture of involvement in context and additional insights into processes, mechanisms, and impacts of involvement. Consideration of the range of impacts identified, and their connection to the rationale for involvement identified a range of conceptual issues related to the outcomes of involvement.

The project's findings have been used to develop new theory-based tools to support the planning, practice and evaluation of involvement. These include a framework for the evaluation of involvement, identification of potential involvement tasks and roles for involvement in health services research, ideas to support thinking about the context of involvement in research, and ways to improve thinking about the range of experiential expertise needed when recruiting research partners.

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## Glossary

AHSN	Academic Health Science Network
BME	Black and minority ethnic
CASP	Critical appraisal skills programme
CLAHRC	Collaboration for Leadership in Applied Health Research and Care
DV	Domestic violence
Health professionals	Doctors, nurses and other clinical staff who provide treatment and care to patients and service users.
INVOLVE	INVOLVE is the national advisory group funded by the NIHR. Its role is to support and promote active public involvement in NHS, public health and social care research.
IRAS	Integrated Research Application System
LINK	Local Involvement Network
Mechanism	Arrangements or methods for doing involvement. This term was also used to cover descriptions of who is involved and involvement processes.
NHS	National Health Service
NIHR	National Institute for Health Research
NRES	National Research Ethics Service
PCPIE	Patient, carer and public involvement and engagement
PiiAF	Public involvement impact assessment framework
PPI	Patient and public involvement

Public involvement in health research	Where research partners assist researchers in the prioritisation, design, conduct and dissemination of health research studies. Terms also used are 'public involvement' and 'involvement'.
PROMS	Patient reported outcome measures
RA	Rheumatoid arthritis
Research partner	Member of the public (who could be a patient, service user or carer) involved in research
Researcher	Staff paid to conduct research including academic staff (working in universities) and health professionals
REC	Research Ethics Committee
TMG	Trial Management Group
UWE	University of the West of England

# Chapter 1: Introduction

## 1.1 Introduction

This doctoral research was conducted from September 2010 to July 2014 at the University of the West of England (UWE) Bristol. It aims to understand what is going on in public involvement in health research, based on an exploration of the relationship between the practice of involvement and conceptualisations of involvement in the literature. Investigation of involvement practice was based on health research case studies, where researchers involved patients, service users or carers in the planning and conduct of research.

I undertook this project because I had been involved in health research as a service user for more than 10 years and was developing a more strategic involvement role. My initial experience was in mental health, including user-led research, working as a paid user-researcher, and leading a research study from 2005-2009. More recently I had helped to build a collaborative regional approach to involvement in health research which included conducting an evaluation of how research active organisations might work together (Davies and Evans 2010). I had also been a service user advisor on the National Institute for Health Research (NIHR) programme grant on suicide prevention for five years, and as a co-applicant since 2013. Alongside conducting this doctoral project, I was a co-applicant on a NIHR funded research study 'Public involvement in research: assessing impact through a realist evaluation' led by Professor David Evans at UWE from 2010-2013 (Evans *et al.* 2014). In 2010 I was appointed as a member of INVOLVE, the NIHR national advisory group on public involvement in health research. Appendix 1 presents additional biographical background information.

At the start of the project I had substantial experience of involvement in research, but limited knowledge of the involvement literature. I was aware of guidance on the practice of involvement, much of it provided by INVOLVE (INVOLVE 2007). The difference between the depiction of involvement in guidance and my experience of it in practice was the starting point of my inquiry. Ward *et al.* (2010) identified a 'know-do gap' between the strong imperatives and policy directives to involve the public and the practice of involvement in research, which had been reported in studies by Telford *et al.* (2002) and Barber, Boote and Cooper (2007). In science and technology studies Delgado, Kjölberg and Wickson (2011) also identified a gap between the theory and practice of involvement.

As my involvement role became more strategic and advisory I wanted to identify tools which would be of practical benefit in the planning, conduct and evaluation of involvement, and I was looking for ways of thinking which would help to bridge the gap between theory and practice.

My focus on the relationship between involvement practice and conceptualisations of involvement in the literature evolved during the early stages of the project, as my ideas developed and I understood the extent to which theories of involvement were contested. As the project progressed I identified an additional aim, to use my understanding of involvement practice to develop practical theoretical tools. In this way the aims of the project evolved over time.

## **1.2 Background**

This section provides a brief introduction to the history and policy context of involvement, to problems of terminology and definitions, and to two important themes in the literature on involvement in health research that shaped the focus of my work.

### **1.2.1 History and policy**

The need to take account of the views of citizens and service users is a consistent theme of healthcare reforms in Europe and North America (WHO 2006) and the UK has been described as being in the vanguard of the promotion of patient and public involvement (PPI) internationally (Tritter and Koivusalo 2013). There has been significant interest in public involvement in health since the 1990's, and requirements to involve patients and the public in the National Health Service (NHS) date back to 1974 and the setting up of Community Health Councils, which were based on a desire for 'consumers' to curb the power of professionals to prevent change (Hogg 2007). Boote, Telford and Cooper (2002) identify that guidance on public involvement in healthcare services can be traced back to the Griffiths Report (Department of Health and Social Security 1983) which recommended that the NHS needed to be more responsive to public needs.

The policy drive for increased public involvement has been characterised as drawing on two groups of ideas based on different philosophical and ideological approaches, one of democratic public involvement (Beresford 2002) and the other a more economically motivated 'consumerist' approach aimed at greater efficiency (Gibson, Britten and Lynch 2012). The democratic approach focuses on people having more influence on organisations which affected them, more control over their lives, and a commitment to personal and political empowerment (Beresford 2002). This approach has drawn on a tradition of activism, particularly in disability and mental health; in contrast the consumerist approach is managerialist and instrumental without any commitment to the redistribution of power or control (Beresford 2005). These different approaches are also characterised as public



involvement based on 'voice' within publicly delivered services or 'choice', drawing on theories of economic regulation (Hughes, Mullen and Vincent-Jones 2009).

The Conservative government in the 1990's sought to change the relationship between the NHS and service users to work along more consumerist lines, associated with the development of an internal market, and the Labour government elected in 1997 continued to emphasise public involvement with a focus on corporate decision making and improving quality (Tritter 2009). Legislation passed in the first 10 years of the 21<sup>st</sup> century has continued to require NHS organisations to engage with service users in the planning and delivery of local services. This legislation includes the *Health and Social Care Acts* (2001 and 2003) which call for greater public participation in decision making processes about provision of healthcare services (Tritter and McCallum 2006), the *National Health Service Act* (2006) and the *Local Government and Public Involvement Health Act* (2007).

The structures to support public involvement in England have been changed a number of times. Community Health Councils were abolished in 2003, and replaced by the Commission on Patient and Public Involvement in Health and PPI Forums, which in turn were abolished in April 2008 and replaced by Local Involvement Networks (LINKs) (Tritter 2009). LINKs were intended to improve engagement with local community and voluntary organisations within a local authority area. The Coalition government elected in May 2010 replaced LINKs with Healthwatch England and local Healthwatch which are argued to undermine public involvement and limit its impact (Tritter and Koivusalo 2013). Gibson, Britten and Lynch (2012) describe these changes as signalling a stronger focus on the consumerist approach to involvement, but in an environment characterised by a universal conviction of the desirability of involvement.

The importance of public involvement specifically in health research is described in *Patient and Public Involvement in the New NHS* (Department of Health 1999) which emphasises involvement in research and development. *Best Research for Best Health* (Department of Health 2006) states that patients and the public must be involved in all stages of the research process, as does the revised *Research Governance Framework for Health and Social Care* (Department of Health 2005). Involvement in research in England is now deeply embedded in NIHR Research and Development strategy, with consistent support from the Department of Health for INVOLVE (Evans 2013). The NIHR asks for information about involvement in all bids for research funding and the National Research Ethics Service (NRES) has similar requirements in applications for approval, with implications for many health researchers. Stewart and Liabo

(2012) describe involvement in research as a requirement for many major health funders in the UK, and argue that ignoring involvement is no longer an option.

While researchers are required to involve the public in health research, there are different interpretations of its aims and benefits, some of which emphasise improvement in the quality of research while others describe involvement as a more political process. The NIHR website states *“involving patients and members of the public in research can lead to better research, clearer outcomes, and faster uptake of new evidence”* (NIHR 2013), and Professor Dame Sally Davies, Director General of Research and Development, Department of Health says:

*No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably makes studies more effective, more credible and often more cost efficient as well.* (Staley 2009 p. 4)

Whereas a systematic review of public involvement in research states

*At its heart, PPI (patient and public involvement) is about empowering individuals and communities, in order that they can play a greater role in shaping health and social care research. In this way PPI aims to democratise health and social care research, to ensure it has maximum health and social benefit.* (Brett et al. 2010 p. 10)

Different understandings of involvement are also identified in practice. In a review of service user involvement in nursing, midwifery and health visiting research, Smith *et al.* (2008) identify different aims for involvement and different outcomes in different contexts. Ward *et al.* (2010) find that researchers focus on how involvement can help their research studies, without recognition of the broader contribution and validity of lay knowledge. In involvement in health service development, healthcare professionals and service users also understand and practice involvement in different ways (Fudge, Wolfe and McKeivitt 2008).

Therefore, policy commitments have extended the reach of involvement in health research without clear agreement about its aims and benefits, and this problem has relevance for many researchers and service users. The next section outlines problems related to the use of terminology and the absence of agreement about the definition of involvement.

### **1.2.2 Terminology and definitions**

The terminology used in public involvement is problematic in a number of respects. It is unclear:

- what to call the people who are involved in research because they have used health services and how to distinguish them from professional researchers
- what to call the arrangements for doing involvement (descriptions of how it is done)

- what to call public involvement
- what public involvement means, because of the absence of agreed definitions, and because in different contexts different words are used for similar activities.

There is significant disagreement between health professionals, researchers and people who use services about what term to use to describe the people who use health services and are involved in research (Beresford 2007). Terms in use include: 'patients', 'service users', 'consumers', 'the public' and 'lay people'; all are contested with different terms preferred in different areas of health research (Boote, Telford and Cooper 2002). For example in mental health the term 'patient' is often rejected, and 'service user' is preferred (Boote, Telford and Cooper 2002), but in other areas of healthcare the term 'patient' is acceptable. Stewart (2013) described further problems including increasing use of the terms 'citizens' and 'members of the community'.

There is no simple solution to this problem, because terminology is linked to the history and cultures of treatment and care in different health areas. In this thesis I have used the term 'research partner' to describe members of the public involved in research. This term has the benefit of clearly distinguishing those who are involved from other patients, service users and the broader public who are not involved. However, some researchers describe organisational or institutional collaborators in research as 'research partners' so the term can be misunderstood, and the use of the word 'partner' could suggest a particular kind of involvement role, an active and collaborative one, but I do not only use the term in this way. Because all terms have both advantages and disadvantages I have chosen to use terminology that no group explicitly rejects, and to avoid more contested terms.

It can be difficult to distinguish research partners from professional researchers. This problem occurs when research partners become paid researchers, as I have been in two roles, where a criterion of employment was being a mental health service user. In these roles I described myself as a service user researcher, but again there is no agreed terminology. In my case studies none of the research partners were employed as paid researchers, so this problem did not arise in the reporting of data. Therefore, I use the term 'researcher' to describe the staff paid to conduct research, including both academic staff (working in universities) and health professionals. I have chosen to use the term 'health professional' to describe doctors, nurses and other clinical staff who provide treatment and care to patients or service users. One of my case studies is in an area where the people receiving treatment and care are described as

patients, in the other the people receiving care are described as service users, and I have used both of these terms in the thesis.

Discussion of involvement includes the identification and analysis of different arrangements for doing it and the terms used for such arrangements vary; including 'mechanisms', 'methods', 'forms', 'structures' and 'approaches'. I have chosen to use the term 'mechanism'; the other term I considered was 'method' but this term can be problematic in involvement in research because of potential confusion between research methods and involvement methods. In making this choice I am following Rowe and Frewer (2005) and Smith *et al.* (2008).

Unfortunately different terms are also used to describe the activity of involvement itself; I use the term 'public involvement', and the word 'involvement' without the prefix 'public', in this thesis. Other terms in use are 'consumer involvement', 'service user and carer involvement', 'patient and public involvement' (often using the acronym PPI) and most recently 'patient carer and public involvement and engagement' with the acronym PCPIE. Similar activities are also called 'public participation' and 'public engagement' in the involvement literature but these terms are problematic in relation to involvement in research because the people contributing to research (research subjects) are called participants, and in research public engagement often refers to the activity of communicating with the public more generally about science. The use of different terms for the activity at the centre of my project signals one of the most important problems in the field, the activity is not something stable, clearly defined and understood.

Some authors distinguish between 'public involvement' in strategic decisions about health services, and 'patient involvement' as the involvement of patients or service users in decisions about their own health care (Florin and Dixon, 2004), but most use these terms interchangeably. These problems are not superficial, they indicate contested theoretical conceptions of involvement and an absence of agreed definitions of involvement (Dyer 2004) and Thompson *et al.* (2009) identify that health researchers understand involvement in different ways.

There have been a number of attempts to define involvement, for example, "*ways in which patients can draw on their experience and members of the public can apply their priorities to the evaluation, development, organisation and delivery of health services*" Tritter (2009 p. 276). Other writers define involvement as a means of influencing decision-making processes in health, including Abelson (2001) and Elberse, Caron-Flinterman and Broerse (2010). Rise *et al.*

(2011) identify a number of definitions of involvement and confirm that none are agreed upon; they find that even though service users and health providers agree on some core aspects of involvement, the value they ascribe to different aspects is different. As a result of these problems Stewart (2013) identifies a need to be clearer about the purpose of involvement activities, arguing that involvement should be accepted as a site of disagreement rather than an unqualified good, and that attempts to define involvement are unworkably vague.

Specifically in relation to involvement in health research there is a definition of involvement provided by INVOLVE (2013) which defines public involvement in research as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. It distinguishes between active involvement in research, participation in research as a research subject and public engagement, where information and knowledge about research is provided and disseminated (see Appendix 2). This definition is widely used in practice and in the literature, for example, recently by Gradinger *et al.* 2013.

While this is helpful, this project aims to investigate the problems of defining involvement and understanding its purpose, so the provision of this definition is not conclusive. In this thesis the term involvement in research is used to describe a situation where research partners, who are most likely (but not exclusively) to be patients or other users of health services, assist researchers in the prioritisation, design, conduct and dissemination of health research studies. Although the INVOLVE definition helps to clarify the difference between public involvement in research, participation in research, and more general public engagement, the literature continues to identify problems with terminology and definitions. For example, in an evaluation of involvement in studies adopted by the Mental Health Research Network, Staley (2012) reports that researchers do not have a shared understanding of what involvement is.

Within the thesis I have chosen some terminology and used it consistently in relation to my own work. However, this is not always possible when discussing ideas from different domains of involvement, for example, in policy formation, commissioning, or service development, or from the literature on the relationship between science and society. Understandings of involvement from different domains cannot simply be translated into a consistent language, because different usages reflect different contexts and meanings. For similar reasons, in reporting data I have adopted terms used by participants rather than imposing terminology on them.

There is another problem with terminology in this project, because I conducted a piece of research and the focus of my research is involvement in health research case studies. To avoid

confusion I use the word 'project' throughout the thesis to refer to my own work and the word 'study' to refer to the health research case studies from which I collected data. While I have adopted strategies to address some of the terminological problems in the field, I cannot resolve the problem that involvement is a contested activity, and I acknowledge that my choice of terms will not be appropriate for all readers.

The literature on involvement in research is characterised by increasing demands for evidence of the effects of involvement. A structured literature review on involvement in research by Staley (2009) reports that researchers find it difficult to assess the impact of public involvement, or understand where it will have greatest benefit, and she calls for research to clarify the added value of involvement in different research contexts. In a systematic review of involvement in research, Brett *et al.* (2010) also call for further research to improve understanding of the impact of involvement. These reviews identify gaps in knowledge about public involvement in health research, and agree on the need to evaluate the impact of involvement. They also identify that involvement is highly dependent on the situation in which it takes place, and therefore that the context of involvement needs to be better understood. Identification of these two key themes in the literature on involvement in research has shaped my project. The calls for more evidence of impact has led to the funding of a range of health research studies to strengthen the evidence base, and my project at UWE was funded in a context shaped by this research environment.

### **1.3 Project aims, questions and design**

The aim of this project is to understand what is going on in public involvement in health research based on an exploration of the relationship between the practice of involvement and conceptualisations of involvement in the literature. My investigation of empirical practice focuses on three health research case studies where researchers involved research partners in the design, planning and conduct of research, to explore, describe and make sense of involvement activities. However, only two case studies are reported in the thesis, one had to be withdrawn in 2014; this is explained in section 4.7.2. The research seeks to provide data about the aims, processes and outcomes of involvement in practice as the foundation for reflection on conceptualisations of involvement in the literature.

### **1.3.1 Research questions**

At the start of the project I developed six research questions to focus my inquiry. These questions are:

1. *What do researchers and research partners do when they work together in research studies?*
2. *How do researchers and research partners describe the experience of working together?*
3. *How does public involvement in research get written about in research related documents?*
4. *Do contextual factors have an effect on public involvement?*
5. *What is the relationship between observed practice, accounts (including written accounts) of public involvement and contextual factors within each case study?*
6. *What are the similarities and differences between data collected about public involvement in the case studies?*

The first question included consideration of what was done, how, when, and where, and on observable impacts of involvement. In relation to accounts of involvement, I was interested in why involvement was done, in participants' motivations, feelings, and perceptions of what difference involvement had made, and whether and how accounts of involvement given by researchers and research partners differed.

The first four research questions complemented each other because they focused on different aspects of involvement with the potential to provide different perspectives on what was going on when researchers and research partners worked together. The last two questions compared data from different sources within each case study and considered the similarities and differences between the case studies.

The methodological approach was qualitative based on realism, reflexivity and abduction with a focus on situated activities. Three case studies were chosen at the start as achievable within the project. To support the exploratory aim of the project, data collection was qualitative and data were gathered by observation, interview and collection of documents. It was important to include observation of public involvement activities alongside accounts of involvement, because of the potential gap between the rhetoric of involvement and its reality. The

difference between what is said about involvement and what is actually done can be described as 'espoused' theories of involvement being different from 'theories in use' (Argyris and Schön 1974).

Data were collected over a period of between thirteen months and sixteen months, from January 2012 to April 2013. My plans for the observation of involvement were ambitious and observations were more limited than I had hoped, but still provided important data. Collection of documents did provide some useful data, but overall data collection was more dependent on interview accounts than I had hoped in my design. My data analysis drew on inductive and deductive perspectives focused both on participants' meanings and themes identified in the literature.

#### **1.4 Involvement in my project**

To ground my project in relevant experience I recruited an Advisory Group. Two members were experienced research partners, the others were a research manager and an academic researcher. The Advisory Group was not involved in the process of designing the project, which started before I was awarded my studentship, but I discussed my initial ideas with other research partner colleagues. The aim of the Advisory Group was to ensure that different perspectives were considered throughout the project, to give feedback, to help with specific tasks and to raise issues of concern. The Terms of Reference for the Advisory Group are presented in Appendix 3.

I recruited members of the Advisory Group by advertising the opportunity on the People in Research website (2014), and through my local network of contacts. Four Advisory Group meetings were held during the conduct of the project, and I also sought feedback between meetings by email. The first two meetings were conducted in early stages of the project, the third meeting took place during data analysis, and the fourth meeting after submission of the thesis. The two research partner members of the Advisory Group were paid for their contributions at the UWE rate, and out of pocket expenses were also covered.

Issues discussed with the Advisory Group included: the role of group members (including discussion of the Terms of Reference) and ground rules for meetings; recruitment of case studies; feedback on participant information sheets; plans for data collection and presentation of data. In addition one pilot interview was conducted, and advice was sought on what findings might be of most practical interest and how they might be disseminated to research partners and practitioners.



## **1.5 Structure of the thesis**

This chapter has provided an introduction to the project. It has briefly reviewed the history and policy context of involvement and the problems with terminology and definitions that characterise involvement, and described the research aims and questions. Chapter 2 provides a literature review which identifies key critical themes and how judgements about involvement practice are made in relation to conceptualisations of involvement. Chapters 3 and 4 describe my philosophical orientation, methodological position and the methods used to conduct the research, including how the case studies were chosen, recruitment of participants, data collection and analysis. Chapter 4 also includes reflection on ethical dilemmas and on my position in the project. Chapters 5 and 6 report the analysis of data by case. Chapter 7 compares the case studies and discusses the findings in relation to current involvement debates. Chapter 8 presents the theoretical tools developed as a result of this project to support better involvement practice. Chapter 9 concludes the thesis by outlining the contribution to new knowledge and reflects on the conduct of the project.

## **Chapter 2: Literature Review**

### **2.1 Introduction**

My thesis investigates the gap between theory and practice in public involvement in research, with a focus on aims, processes and outcomes of involvement. This literature review identifies key critical themes in the literature in order to understand what, how, and why practice can fail to deliver. In addition, the literature review seeks to understand the basis upon which judgements are made about involvement practice and to identify significant theories and issues of importance to involvement.

A number of key critiques are identified. The first emphasises that involvement practice often fails to deliver on desired objectives, where potential benefits are resisted by professionals, and involvement becomes a legitimisation strategy for institutions or those in positions of power. A second critique argues that the wrong people are involved and, as a result, involvement practices suffer from problems of legitimacy. A third critique is that insufficient attention is given to the outcomes of involvement. The rationales of involvement that underpin these judgements are reviewed, identifying tensions between different rationales, and the absence of links between desired outcomes, rationale and evaluation.

The literature review identifies a theoretical concern about the nature of experiential expertise and its relationship to professional expertise and knowledge. While there is consensus that the context of involvement is significant, there are different ideas about how such influences might be conceptualised, and little understanding of how to consider their influence on practice. The review identifies five key process criteria of importance for the conduct of involvement.

The review identifies a number of significant issues and draws out key components of involvement which are: rationale, legitimacy of those involved, a need to focus on outcomes, alongside the importance of both context and process. These components are then used to review current conceptualisations of involvement, and their potential to underpin evaluations of involvement practice, in order to identify the models with most potential to reduce the gap between theory and practice. The next section outlines the methodology and approach taken to conducting the literature review.

## 2.2 Methodology and approach

The literature review takes stock of published evidence about public involvement. The approach is based on narrative analysis to provide an overview of the literature and is influenced by the description of critical review in the typology developed by Grant and Booth (2009). This kind of review is described as an evaluation of what is of value from the previous body of work that presents analyses and synthesises material from diverse sources. The review addresses a number of issues of importance. Articles for inclusion were identified based on the following topics:

- definitions of public involvement
- conceptualisation of public involvement
- critiques of public involvement practice
- the impact or outcomes of public involvement
- the context of involvement.

Problems have been identified in conducting literature reviews in involvement. Both Staley (2009) and Brett *et al.* (2010) found relevant articles difficult to identify for their reviews because of inconsistencies in the terminology used for involvement, and inconsistencies in reporting involvement. Quality assessment of studies is problematic; Staley (2009) found it impossible to judge the quality of the evidence or assess whether results were generalisable. Brett *et al.* (2010) also identify difficulties in assessing quality, in part because existing tools were developed to measure the quality of a study not the quality of the involvement activity, and use of Critical Appraisal Skills Programme checklists (CASP 2013) generated little difference between papers in their systematic review. In addition, they found it problematic to exclude studies based on design, because involvement studies used variable designs and included many qualitative and case studies, reflecting a diverse and complex field. Although Wright *et al.* (2010) have developed guidelines for the assessment of the quality and impact of involvement in research in published studies based on CASP, the guidelines were described as only useful for what they described as pragmatic involvement (focused on outcomes on research). Their criteria were not seen as relevant for studies adopting a democratic ideological perspective. This limited their applicability for this literature review which aimed to include different conceptualisations of involvement.

The literature review was conducted in two phases. The first phase took place from 2010-2011 and focused on public involvement in research. The starting point was two recent reviews, the first published by Staley (2009) which focused on exploring the impact of involvement in

research, and the second, a systematic review of the conceptualisation, measurement, impact and outcomes of involvement in health and social care research published by Brett *et al.* (2010). There was little point duplicating these large externally funded reviews, so a key part of my strategy was utilising their existing searches to interrogate the data in relation to my areas of interest. Reference lists and data extraction tables for both reviews were searched for relevant articles. Staley (2009) identified 89 relevant articles, Brett *et al.* 2010 included 90 after assessment. Phase 1 also drew on two bibliographies, one compiled by Boote (2011) and the second published by INVOLVE (2010b) which reflected an evidence library developed since 2007. The INVOLVE bibliography provided abstracts of references that covered the nature and extent of involvement in research, the impact of involvement on research and reflections on involvement. This bibliography was updated during my project, and I also reviewed articles listed in the revised bibliography (INVOLVE 2012a). These strategies identified an additional seven articles not included by Staley (2009) and Brett *et al.* (2010). The abstracts of all references identified as potentially relevant were screened initially, and the full text was used where the title and abstract were inconclusive.

The second phase of the literature review was conducted in the second half of 2013. This phase included literature on involvement in service improvement and policy development across health and social care. Selection of search terms and electronic databases were guided by the prior reviews (Staley 2009 and Brett *et al.* 2010) and discussion with supervisors. The search terms used to identify literature are shown in Table 1, and the search also included reference lists from eligible studies, prior reviews in the field and grey literature.

**Table 1: Search terms**

<b>Public</b>	<b>Health, public health and social care</b>	<b>Area</b>	<b>Involvement</b>
carer	health	UK	consult
citizen	health care	Australia	collaborate
client	health service	Canada	emancipate
consumer	primary health care	Europe	empower
family	public health	North America	engage
lay	social care		involve
patient	social service		partnership
public			participate
service user			
user			

The databases searched are listed in Table 2.

**Table 2: Databases searched:**

<b>Databases</b>	<b>Topic area</b>
ASSIA	Social sciences
CINAHL	Nursing and allied health
Cochrane library	Medicine
Embase	Medicine
Medline	Medicine
PsycINFO	Medicine
Social Care Online	Social care
Social Science Abstracts	Social sciences

A large number of papers were identified in phase two (>5,000) after checking for duplicates, but screening of titles and abstracts using my inclusion criteria reduced the number to 168. The inclusion criteria were relevance for the five topic areas identified above, articles in the English language, and publication between 2000-2013. Papers were not screened for quality given the difficulties reported by Staley (2009) and Brett *et al.* (2010) above, but for relevance to my topics of interest. Following screening an in-depth review of the included articles was conducted. A narrative analysis was conducted which involved initial familiarisation with the papers. The five topics were used to index papers and sort the findings, and relevant information was recorded by these themes. Subsequent readings identified of sub-themes. Emergent themes were added, for example, the rationale of involvement.

Conducting the literature review was a challenging process for a number of reasons. While a structured search and review process was undertaken, additional articles were identified by review of citations. While it was helpful to have access to bibliographies, systematic reviews and search strategies that had been used before, the volume of literature identified was large. Search terms which described involvement were not consistent, and it was often unclear from abstracts whether or not individual articles were relevant, which meant reviewing the full text of many articles. This made selecting relevant articles challenging.

The literature review reports synthesised findings from both phases. The findings of the literature review are reported in relation to key critiques of practice that were identified as important, followed by important themes related to the conceptualisation, context, practice and impact of involvement.

### 2.3 Can involvement deliver desired aims?

Chapter 1 identifies that involvement might have different aims, in particular including a democratic approach which includes increasing personal control and empowerment, a consumerist approach to improve efficiency (Beresford 2002) and a focus on improving research quality (Ward *et al.* 2010). Despite ongoing policy commitments to involvement the literature presents a number of key critiques of involvement practice which focus on the failure to deliver on desired objectives.

One early critique is articulated by Harrison and Mort (1998) who conclude that while involvement is broadly endorsed in principle there is significant disagreement about it in practice. Findings demonstrated lack of commitment to be bound by the outcomes of involvement activities if they did not serve professionals' purposes. They describe involvement phenomena as social technologies of legitimation for decisions and activities of NHS agencies, arguing that involvement is very much concerned with building acquiescence with decisions and deflecting criticisms of lack of democracy. As the NHS is based on a network model of social co-ordination, it produces implicit bargains functioning for the benefit of insiders, which makes it difficult to legitimate. Involving the public is, therefore, an obvious means of enhancing legitimacy, but in their empirical examples professionals remained very much in control.

This critique is echoed in widespread criticisms of 'consumerist' involvement. Harrison, Dowswell and Milewa (2002) describe notions of consumerism as focused on matters of information and consumer choice linked to literatures of marketing and market research, quality assessment, quality control and quality assurance. Consumerist involvement, therefore, is reliant on the assumption that health care providers should be responsive to patient demand. Rowe and Shepherd (2002) describe the medical dominance of health services as being challenged by efforts to subject the NHS to financial and managerial discipline focused on value for money, where involvement is a route to increasing efficiency. Despite the rhetoric of partnership, the public are not considered equals in policy making; instead, responsibility for determining the interests of the public is shared between medical professionals and health service managers and involvement is perceived as a means of informing decision makers who would balance public views against other information in developing services. Wait and Nolte (2006) suggest that economists advocate this kind of involvement to correct inherent failures in health care markets, including information asymmetry, difficulties in product evaluation, and the high cost of error. Tritter (2009) links consumerism to redefining relations between the state as guarantor of the health and

wellbeing of citizens, to the state as promoter of markets. He referred back to Ignatieff (1995) who describes consumerism as a symptom of the crisis of citizenship, where most political rhetoric addresses the electorate as taxpayers or consumers, and the market determines the language of politics.

Many authors are critical of consumerist involvement; Beresford (2002, 2010) depicts it as market driven, overlaid with managerialist ideas and philosophy, where the aim is to draw in views to inform and legitimate the actions of existing decision makers and power holders. Smith *et al.* (2008) describe consumerism as driven by attempts to meet increasing demands on health services, where involvement is top-down. Martin (2008a) reports a sustained attack on consumerist models of involvement deployed alongside the internal market in the NHS in the UK. Gibson, Britten and Lynch (2012) identify consumerist involvement as a weak and predominantly instrumental approach, and argue that involvement structures in the NHS are unlikely to provide an effective response to the plurality of values, ideologies and social groups.

Related critiques of involvement practice are focused on how the capacity to deliver desirable objectives can be constrained by the involvement mechanism chosen, and how involvement activities are conducted. Such critiques emphasise how professional control of such issues can undermine the scope of involvement. Harrison and Mort (1998) describe involvement in health panels in the UK and identify that time for discussion between those involved, and whether or not relevant information is provided, have implications for the scope of involvement activities. Barnes *et al.* (2003) conducted seventeen case studies in two cities in the UK, which report that while the terms of involvement are negotiated between the public and professionals this is not an equal exchange. Institutions have financial resources, formal authority, and control agendas. Braun and Schultz (2010) provide analysis of the productive dimensions of involvement practices, including processes of framing, staging, selection and priority setting, attribution, interpellation, categorisation and classification.

### **2.3.1 Discussion**

This section has identified a number of key critiques of involvement practice. Such critiques, while valid, ignore the fact that institutions, and the professionals working in them, are required to use organisational resources to address priorities and issues identified as important from an institutional perspective, not to pursue social justice. Therefore, it is not surprising that policies requiring involvement in health are interpreted to serve organisational, rather than democratic, interests.

These critiques are based on normative understandings of involvement, where legitimate involvement is intended to change social relations by promoting democracy and social justice. When involvement practice becomes a technology of legitimation, a market driven consumerist approach, or when the scope of involvement is determined by professionals, instead of pursuing desired aims, involvement is being deployed to sustain existing power relations and to meet managerial and instrumental aims. Crawford, Rutter and Thelwall (2003) depict such critiques as professional resistance to desirable outcomes of involvement. While these critiques are valid in relation to democratic aims, they evaluate involvement practice from one perspective. By implication other aims of involvement, to improve efficiency, or to improve the quality of health research, are dismissed as lacking legitimacy or potential benefit. The implications of using such normative views of the purpose of involvement for the understanding and evaluation of practice are considered further in section 2.6.

## **2.4 Are the 'right' people involved?**

Another core critique in the literature focuses on the question of who should be involved. Critics emphasise reliance on the same traditional middle-class selection of citizens to represent the interests of all (Church *et al.* 2002). Martin (2008b) observes that much involvement fails to reflect the characteristics of wider society and relies on the self-selection of 'appropriate' or acquiescent individuals. Evidence confirms that those getting involved in public life are more likely to be older, from white ethnic groups and higher socio-economic backgrounds (Pathways through participation, 2009), and may have a limited range of experiences and perspectives to draw upon (INVOLVE 2012c). The involvement of elitist, selected and wealthier groups compromises the governance of health research because large swathes of the public are not included, in particular socially marginalised groups (Robinson, Newton and Dawson 2012).

Some social groups experience greater ill health, disability and reduced life expectancy than others (Black 1980), and inequalities by ethnic group and gender are demonstrated across a wide range of measures of health (Acheson, 1998). In 2010, the Marmot Review concluded that health inequalities are a result of social and economic inequalities across the population, "*put simply, the higher one's social position, the better one's health is likely to be*" (Marmot 2010, p. 10).

On these grounds greater diversity is often recommended (INVOLVE 2012c). However, organisations working to promote diversity and increase inclusion argue that involving people from diverse backgrounds requires real commitment to equal opportunities and



implementation of effective practical measures (Joseph Rowntree Foundation, 1996) and it is unlikely that achieving greater diversity and inclusion will come through 'quick fix' solutions (INVOLVE 2012c).

Other critics emphasise professional control of involvement; in their case studies Barnes *et al.* (2003) describe how publics are constituted by professionals who define who takes part. Braun and Schultz (2010) report that control over the construction of publics privilege governments and organisers of involvement events in science, and that different formats and mechanisms of involvement construct different publics. They argue that "*a certain amount of engineering*" is necessary in constructing the public (Braun and Schultz 2010 p. 403).

Increasing the diversity of those involved is widely endorsed in the literature and professional control of who takes part is criticised. However, lack of diversity can be used as an argument to undermine the contributions and credibility of those who are involved.

#### **2.4.1 Representativeness and legitimacy**

Crawford, Rutter and Thelwall (2003), in a substantial review of involvement in health services, report that statements about representativeness are very common but that the meaning of the term is rarely considered. In their empirical work Barnes, Newman and Sullivan (2004) find that concepts of representation and representativeness are crucial resources in negotiations of legitimate membership, informing conflict over legitimacy claims, and identify that political concepts of representation and statistical concepts of representativeness are often confused. Martin (2008b) observes that much of the involvement literature focuses on issues of representativeness.

Tensions between different understandings of representation make it clear that what it means in involvement is disputed. Where the meaning of representativeness has been explored there is little consensus; for example, Litva *et al.* (2002) describe four broad types of representation in health care which include elected representation in government, advocacy by experts on behalf of patients, random samples of citizens in a locality and representation by special interest groups. However, Contandriopoulos (2004) uses Pitkin's (1967) analysis of representation and focuses on three dimensions for involvement:

- formal representation which refers to representation by election or random selection
- descriptive representation which refers to the degree to which representatives are similar to the 'average' represented, often in relation to characteristics of a specific population
- symbolic representation which derives from subjective perceptions of legitimacy.

Contandriopoulos (2004) argues that because involvement in health draws less on formal and descriptive representation it is characterised by symbolic struggles to appropriate the intrinsic legitimacy of the public. Other understandings of representativeness include, for example, Martin (2008a) and Robinson, Newton and Dawson (2012) who argue that improving representation in relation to descriptive demographic characteristics does not provide more accurate representation of expressed opinion, and also describe 'experiential representation' based on shared experiences as enhancing legitimacy.

Legitimacy and representation are contested in different ways. While involvement of the politically active is valued by Williams and Popay (1994), Epstein (1995), and McCormick *et al.* (2004) as the inclusion of grass-roots and partisan activists, Barnes, Newman and Sullivan (2004) find that while citizens sought legitimacy from a history of activism, officials sought broader 'representative' participation from local residents. Braun and Schultz (2010) also report that activists are seen as unrepresentative of broader patient populations by professionals.

Concerns about who should participate have been identified as being of particular interest in policymaking in health (Lehoux, Daudelin and Abelson 2012). Here the political legitimacy of public involvement is a prominent concern, and disinterested citizens are desired as able to provide a more legitimate input, and to balance the playing field too easily dominated by strong interests (Evans and Plows 2007). Again inclusion of grass roots movements and activism is problematic (Barnes 2008). However, Lehoux, Daudelin and Abelson (2012) argue that such understandings of citizenship suffer from 'lightness', which need to be given more depth based on citizens' cultural, relational and cognitive resources including their lived experience. Martin (2012) also critiques the desire for the 'ordinary citizen' based on involvement of abstracted and 'unhyphenated citizens' (Davies, Wetherell and Barnett 2006), arguing the focus should be on sociologically concrete citizenship and understanding of how it can be embodied and exercised in involvement.

Different understandings of representation, alongside frequent reference to it as an important issue, indicate an outstanding problem for involvement practice and evaluation. Challenges to involvement practice on the basis of representation and legitimacy are not straightforward to understand or remedy because the basis of legitimacy is contested. Legitimacy has been associated with the inclusion of interest groups and activists, embodied and concrete citizenship derived from lived experience, 'ordinary' and disinterested citizens, and representation of broad patient populations. Section 2.4.3 identifies another way in which legitimacy is contested – when members of the public become involvement 'professionals'.

## 2.4.2 Conceptualisations of the public

Consideration of who should be involved is also related to different understandings of what might be meant by the public in the involvement literature. Some writers have used the idea of interests to distinguish between publics; Charles and DeMaio (1993) identify two perspectives, the 'user' with narrowly defined interests, and a 'policy' perspective where views reflect a broader public or community. Harrison, Dowswell and Milewa (2002) and Coulter (2006) argue the importance of distinguishing between patients and service users and the more general public or citizens because the interests of the two are not identical. For example, if you have a particular condition your interests are in better specific services for yourself and people like you, but if health is generally good, interests focus on a broad range of services being available, balanced against a desire to pay a reasonable level of tax.

Michael (2009) differentiates between publics-in-general (PiGs) and publics-in-particular (PiPs). PiGs are characterised globally and echo discourses of society; some negative, as ignorant of science or more or less irrational, or more positively with the capacity to deliberate, participate and engage. Positive views moralise citizenship, where those who participate are good. PiPs are publics with an identifiable stake in particular issues or programmes of research, based on local knowledge, experience or an internal condition. Michael (2009) identifies PiPs as able to claim legitimacy and authenticity based on the reality of their position, whereas PiGs lack location.

Braun and Schultz (2010) identify four constructions of the public, 'general', 'pure', 'affected' and 'partisan' based on studies of involvement in genetic testing in Germany and the UK. They find that constructions of a 'pure' public exclude those with strong opinions, that the 'affected' public (with first-hand personal experience) is seen as the authentic public, whereas 'partisan' publics are characterised as minority vociferous groups of activists without democratic legitimacy.

These conceptualisations of the public establish an important distinction, between the more general public and those with relevant personal experience, and that these groups may have different interests in involvement. They also reflect different legitimacy claims as discussed in the previous section. Martin (2008b) argues that concerns about representativeness are more prominent when involvement focuses on the more general public than in involvement of those with relevant experience.

### 2.4.3 'Professional' or 'ordinary' publics

This theme concerns the relative desirability of 'ordinary' or 'naïve' patients and service users, in contrast to 'professional' research partners with involvement experience (like me).

Some authors value professionalisation; in the field of disability Beresford and Campbell (1994) argue that, as professional service users, they are unrepresentative in ways some service providers do not want, being confident, experienced, informed and effective. Epstein (1995) describes how AIDS activists became proficient in scientific terminology, epidemiology and treatment discourses in order to gain acceptance in the scientific community, and McCormick *et al.* (2004) describe similar processes in breast cancer research. Here development of relevant additional expertise is valuable.

In contrast, Learmonth, Martin and Warwick describe a 'Catch-22' situation in involvement as *"you have to be ordinary to represent the community effectively, but, if you are ordinary, you cannot effectively represent your community"* (2009 p. 106). Here being 'ordinary' is a desirable but undefined characteristic which conflicts with other expectations, for example, gathering information from a wide range of people in communities, having an understanding of the health needs of the community, and commitment of substantial amounts of unpaid time. When 'ordinary' people try to meet such expectations they became quasi-professionals and, therefore, unrepresentative and undesirable.

Michael (2009) characterises affected publics as either radical or reformist; radical publics are at a distance from science and based in grass roots movements while more reformist publics are criticised as being incorporated into science. Abelson *et al.* (2003) describe how users exposed to the complexities of the health system became sympathetic to the challenges faced by decision makers, and a danger that they might lose their lay perspective and be co-opted by the involvement process. Thompson *et al.* (2012) explores different understandings of involvement roles in cancer research, and finds that those involved value expertise from other fields, gaining specialist knowledge and training as sources of credibility. Such professionalisation raises questions about whether experiential expertise is sufficient to establish credibility. Because those involved defer to the knowledge of experts and do not challenge professionals, Thompson *et al.* (2012) suggest that such involvement serves expert interests instead of public interests. Here expert and public interests are assumed to conflict, however another view is possible, that patients and researchers see themselves as working together to improve treatment and care, where they can pursue shared interests.

Ives, Damery and Redwood (2012) argue that the concept of involvement in research is incoherent, because the real value of involvement is being an outsider, free of cultural or institutional pressures but lay knowledge is insufficient in a domain of expertise. Therefore those involved need training and information which leads to professional socialisation. However, Staley (2013) counters that people do not lose their lay perspective as a result of training, and nor are they being turned into professional researchers because training is limited to understanding of the basics of research, and I agree with this view.

#### **2.4.4 Discussion**

This section has outlined critiques of who is involved; there is consensus that increased diversity is desirable, and that the concept of representation is important. However, there are different understandings of what representation means in involvement and many other issues are also contested. In particular there are different understandings of who makes legitimate contributions. Martin (2012) suggests that the purpose of involvement is often to ensure representation of the 'public at large' and avoid capture by pressure groups (Irwin 2006). The desire is for "*those reason-giving, reason-receiving citizens of political theory*" (Martin 2012 p. 1852), but many studies highlight the problems of identifying and bringing such a public into involvement processes. Such views contrast with the desire to involve of politically active patients and service user groups (Popay and Williams 1996; Beresford 2010).

Relevant personal experience has also been seen as the basis for authentic involvement. Barnes (2008) argues that those most affected by social issues should be included rather than excluded, and that involvement fora need to support expressions of values and emotion as legitimate and important contributions. Indeed she suggests that involvement mechanisms should be judged on their capacity to encompass such expression, rather than exclude it. Such views challenge the desire for disinterested and 'ordinary' citizens; instead involvement of people with active interests is legitimate, including political, normative and emotional expression of such interests. The range of views about what constitutes legitimate involvement is a key problem for the evaluation of involvement practice.

The distinction between a more general public and those with relevant personal experience is helpful, and different conceptualisations of the public have been associated with different concerns about legitimacy, where involvement of a more general public orients questions of legitimacy to representativeness, and involvement of the affected public to challenge on the basis of undesirable professionalisation and incorporation.

Some argue that gaining knowledge and experience increases the effectiveness of involvement. In contrast, arguments of co-option and incorporation rest on the loss of critical capacity once socialised in a professional domain with the assumption that the absence of direct challenge to established power relations renders involvement impotent. However, this loss of critical capacity is not applied to researchers who have institutional roles in the NHS, universities or research infrastructure, and it is unclear on what basis academics are immune from these processes. Such views are inconsistent and deny the complexity of multiple social and professional roles.

## **2.5 Outcomes of involvement**

A third critique in the involvement literature is that there is insufficient focus on the outcomes (or impacts) of involvement. Rowe and Frewer (2000) have done extensive work on the evaluation of involvement in agenda-setting, decision-making and policy-forming activities. They argue that the outcome of involvement should have a genuine impact on policy and should be a key evaluation criterion. Harrison, Dowswell and Milewa (2002) propose that there should be more focus on outcomes instead of descriptive accounts of involvement. They suggest a need to identify aims of involvement, to link processes of involvement to outcomes, and provide accounts of changes made as a result.

Abelson *et al.* (2003) propose that the effectiveness of involvement should ultimately be judged by some measure of the outcomes achieved, noting the debate in the literature between those concerned with process measures and those concerned about differences to health decisions taken. Reviews of involvement also identify the need to focus more on impact, for example, both Simces and Associates (2003) and Crawford, Rutter and Thelwall (2003) identify that emphasis in the literature is on the process of involvement not outcomes, and that the experience of involvement is often seen as an outcome, rather than impacts on services or patients' health. In response, Mockford *et al.* (2012) and Conklin, Morris and Nolte (2012) reviewed outcomes on health-care policy and found that evidence of impact was scarce.

In involvement in research Boote, Telford and Cooper (2002) identify a lack of knowledge of the effects of involvement, and pose questions in need of theoretical and empirical attention including how and why involvement has an impact and how it could be measured. Wright *et al.* (2010) propose that critical appraisal should demonstrate 'added-value', identify what difference involvement has made to a study, and include impacts on the length of a study and

costs of involvement. Staniszewska *et al.* (2011a) argue that the evidence base for involvement in research needs strengthening by the measurement of impact.

There have been a number of reviews of involvement in research which focus on outcomes. Smith *et al.* (2008) investigate nursing and health visiting research and hypothesise that empowerment of research partners is likely to be associated with positive involvement processes. In contrast to authors above, they recommend that outcomes should focus on improving research processes and on outcomes for researchers and service users rather than outcomes on research. This is because research outcomes are difficult to predict due to contextual factors, there are many different involvement mechanisms, and research relationships are complex. Evans *et al.* (2014) find that involvement could improve recruitment strategies and materials but might not actually improve recruitment, so impacts on research may improve the quality of research processes without necessarily affecting research outcomes.

Staley (2009) reviews impact in health and social care research, and finds a range of impacts including on research, on members of the public, on researchers, on research participants, community organisations and the wider community. In a systematic review of the conceptualisation, measurement, impact and outcomes of involvement Brett *et al.* (2010) also identify different kinds of impacts, including positive impacts on the quality and appropriateness of research and some challenging impacts, and theorise that evaluation of impact is a complex process dependent both on involvement processes and the context of involvement. However, a review by Shippee *et al.* (2013) provides a framework for involvement in research which emphasises the quality of involvement processes rather than outcomes.

Work on impacts of involvement in research has identified a range of impacts, including on research, on research partners and researchers and other stakeholders, but some suggest that evaluation should continue to focus on the evaluation of involvement processes rather than outcomes. In addition, the feasibility of measuring impact has been questioned by Barber *et al.* (2011). Using a consensus process they identify 16 impact issues (see Appendix 4), which include seven outcome areas, but there is only agreement on the feasibility of evaluating five of the 16 factors. Two relate to research processes (identifying topics to be researched, prioritising topics to be researched), two to impact on stakeholders (members of the public and researchers) but only one research outcome (dissemination of research findings). The identification of impact factors is helpful, but this work reinforces doubts about the feasibility of assessing impacts on research outcomes.

There has been some work on the conceptualisation of impacts. In policy development Restall (2013) conceptualise outcomes as micro (personal), meso (substantive and instrumental) and macro (normative). In involvement in research the absence of focus on negative impacts has been identified (Smith *et al.* 2008; Brett *et al.* 2010; Wright *et al.* 2010). Recently, a public involvement impact assessment framework (PiiAF) has been produced for involvement in research (Popay and Collins 2014) with guidance for undertaking assessments. This two part framework facilitates the production of an impact assessment plan. Part 1 has five elements for consideration before decisions are taken about how to assess impact, and this includes different kinds of impact (on research, on people, short or long term, positive or negative) which are also described by Staley (2009) and Brett *et al.* (2010). Part 2 includes laying the foundations for impact assessment, developing an intervention theory, identifying possible effects of context on impacts of involvement and formulating assessment questions and study design. The PiiAF process situates involvement as a complex intervention, and provides a detailed and in-depth process to assess impact.

### **2.5.1 Discussion**

A number of authors identify a need for more focus on outcomes of involvement, and this is a strong theme in involvement in research in particular. However, some authors emphasise impacts on policy, services, research and health, while others continue to emphasise outcomes related to involvement processes and on research partners and researchers. While impacts on research are identified (Staley 2009; Brett *et al.* 2010), the feasibility of measuring outcomes is questioned (Barber *et al.* 2011). While interactions between process, context and outcomes are identified as important (Brett *et al.* 2010) it is not clear how to assess them.

In involvement in research authors categorise outcomes in similar ways (Staley 2009; Brett *et al.* 2010; Popay and Collins 2014), however, they do not include normative outcomes proposed by Restall (2013). While there is now an impact assessment framework for involvement in research (Popay and Collins 2014) the framework includes consideration of a whole range of issues including underpinning values, approaches and practical issues in developing an impact assessment, and does not only focus on outcomes on research. While comprehensive, this framework is likely to require significant additional resources which may make it impractical to use for many researchers.

There is a significant gap between the current approaches to identifying outcomes and the kinds of impacts identified, and the desire to identify impacts on health policies, services, treatments, research and patient health. In involvement in health research in England, the NIHR emphasises that the public can make a difference to research by identifying new



research topics of relevance for service users, make sure researchers ask the right questions, approach research participants in the right way, and improve the quality of research (NIHR 2013). The desirable outcomes identified in policy and the literature in this section are significantly different from the concerns identified in section 2.3 which focused on why involvement doesn't deliver on improvements in democracy and social justice. Identification of this divergence draws attention to the connection between different aims of involvement and outcomes. The next section considers the key critiques identified in sections 2.3-2.5 in relation to underpinning understandings of the purposes of involvement.

## **2.6 Key critiques and rationale for involvement**

The critiques of involvement practice identified in section 2.3 are described as being underpinned by normative understandings of legitimate involvement, which emphasise improvements in democracy and social justice as desirable outcomes, where involvement is a tool to change social relations. The first part of this section reviews this rationale for involvement, which is followed by a review of involvement oriented towards outcomes on health, research, treatment and care.

### **2.6.1 Normative rationale of involvement**

Harrison, Dowswell and Milewa (2002) identify a body of involvement literature focusing on democracy and citizenship, which distinguishes concepts of representative or liberal democracy from direct or participative democracy. The latter stress political participation as an end in itself, as a means of developing citizens and improving political decisions and protecting citizens from others making decisions against their interests. In contrast, representative democracy provides the model of elective political offices. There has been much interest in the literature in deliberation as a desirable form of participatory democracy. Abelson *et al.* (2003) report on a deliberative paradigm of involvement which emphasises two way interactions between decision-makers and the public, drawing on the idea that deliberation is seen as the essence of democracy (Dryzek 2000). Deliberation here is understood as a process of careful and serious discussion of issues where authentic reflection leads to an alteration of views.

A second strand of normative involvement theorises a shift from government to governance. Newman *et al.* (2004) situate involvement in conceptions of governance that result from the transformation of modern states. They describe the emergence of multi-level governance in the light of complex social issues which elude traditional approaches to governing through hierarchical instruments of control. Shifting from direct control to governance means the state

must collaborate with a wide range of actors in networks that cut across the public, private and voluntary sectors, operating at different levels of decision making.

Another related focus is on increasing accountability within the NHS which has been described by Litva *et al.* (2002) as stemming from the fact that the NHS is publicly funded and that managers and health professionals should be accountable to actual and potential patients and publics. Abelson *et al.* (2004) identify that efforts to consult citizens in the UK and Canada are based on a commitment to address concerns regarding the health system's lack of transparency and public accountability at all levels of government. Tritter and McCallum (2006) describe the main focus of involvement as the requirement for health services to be accountable to users as taxpayers, voters and consumers.

Normative involvement is also connected to the resolution of a range of political problems, including overcoming the decline of interest in party politics, and dealing more effectively with questions of identity in a multi-cultural and global/local world (Newman *et al.* 2004). For Martin (2008a) involvement addresses the 'democratic deficit' and Gibson, Britten and Lynch (2012) suggest involvement is a governmental response to a complex array of major legitimisation crises.

Alongside these understandings are ideas about involvement conceived as proactive social action. Harrison, Dowswell and Milewa (2002) identify a body of involvement literature relating to pressure groups, networks and new social movements. Self-organised pressure groups are seen as a means by which individuals can represent their interests to government potentially dominated by professional or economic interests. New social movements are seen as distinct from pressure groups, being broader based and held together by a community of identity rather than of interest, this includes the large number patient groups in the health sector. Beresford (2010) argues that the disabled people's movement in the UK has developed an independent agenda, rather than working in partnership with the state, focused on alternative approaches to policy and provision. He argues that such involvement is valuable as a means of making change, with an emphasis on equalising civil and human rights, seeking a greater say, and redistribution of power and control.

However, social action has also been characterised more negatively as serving the narrow interests of patients or groups of service users. Litva *et al.* (2002, 2009) describe involvement as essentially self-interested with a focus on getting the best treatment and care. Martin (2008a) suggests that the impact of AIDS activists on clinical trial methodology described by Epstein (1995) could be seen as an undemocratic influence of an organised pressure group on

priorities. Both individual and collective involvement is presented as self-interested political action, which does not necessarily promote the interests of all.

In addition to critiques of involvement practice described in section 2.3, some critiques of those involved in section 2.4 are also oriented to the normative rationale. This includes the desirability of radical rather than reformist publics (Michael 2009), the problematic potential for users to become co-opted and to sympathise with problems faced by decision makers (Abelson *et al.* 2003) alongside a critique of professionalised users who defer to expert knowledge and do not challenge professionals (Thompson *et al.* 2012). Such critiques suggest that involvement should be adversarial and challenge professionals' power, however, empirical investigation of the roles wanted by members of the public do not confirm this desire for responsibility (Litva *et al.* 2002; Litva *et al.* 2009). The lack of empirical support for an adversarial involvement role emphasises the value based underpinning of this rationale.

### **2.6.2 Alternative rationales of involvement**

While normative understandings of involvement underpin some key critiques of involvement and are pervasive in the literature, Cayton (2004) identifies that the purpose of involvement is an outstanding issue for discussion, asking whether it is to improve health outcomes, health service delivery or patient experiences. Bochel *et al.* (2008) argue that involvement might be intended to improve governance, democracy, social capital, education, or the development of individuals, policies, service implementation and delivery, or something else altogether. Other authors have reported unclear roles for research partners (Dyer 2004), a conceptual muddle within which involvement is articulated, understood and actioned (Forbat, Hubbard and Kearney 2009), and terminological instability which "*denotes disagreement about the nature and purposes of participation*" Stewart (2013 p. 124). It seems, therefore, that the purpose of involvement in health and social care is not agreed as aligned with normative understandings of involvement. The failure of involvement to deliver on democracy and social justice cannot therefore be understood as an over-arching failure, because it may have been undertaken with other purposes in mind.

In contrast to the normative rationale, involvement in health also focuses on the consequences of involvement to improve something, which might be health policies, treatments, care, services, education of professionals, research or individual/community health. Some authors describe this as a consequentialist rationale for involvement (Thompson *et al.* 2014). Caron-Flinterman *et al.* (2006) distinguish normative arguments for involvement, reflecting political concerns, from substantive arguments focused on the consequences of involvement. In involvement in research Oliver *et al.* (2008) distinguish between political

mandate, which could be satisfied by tokenistic public presence, and the pursuit of 'better' research. Elberse *et al.* (2010) identify three different rationales; first, to increase the quality and relevance of health research because experiential knowledge complements the scientific knowledge of experts, what they call a substantive argument; second, that patients have the right to be involved because they are affected by the outcomes of health research, a normative argument; and third, that involvement can lead to a better acceptance of research and its outcomes by patients which they call an instrumental argument.

The previous section identifies the need for increased focus on the outcomes of involvement on policy, services, research and health, including outcomes relating to involvement processes and on research partners and researchers. I have chosen to describe the aim of such involvement as substantive, distinguishing it from the normative rationale and an adversarial involvement role. Evidence that many people work in alliance with experts for substantive purposes without obvious desire to challenge power relations is evaluated critically (Kerr, Cunningham-Burley and Tutton 2007; Weiner 2009; Thompson *et al.* 2012). However, from the perspective of a substantive rationale, partnership working and shared interests are a positive way to improve research, treatments and care. Acknowledgement of shared interests supports a view of involvement which is not necessarily adversarial, where involvement makes a contribution within existing structures of social relations, and developing experience of involvement might be beneficial rather than undesirable professionalisation. In such ways, substantive involvement may be located within dominant paradigms and provide legitimate benefits.

### **2.6.3 Discussion**

While the key critiques of involvement practice described in section 2.3 remain important if the purpose of involvement is to improve democracy, accountability, governance and social justice, this is not the only legitimate purpose of involvement activity. This means that key critiques based on a normative rationale cannot be understood as having universal relevance to all involvement practice. If the rationale for involvement is substantive and oriented to outcomes focused on improving research, health treatments and care, some key critiques may not be relevant because the relationship between such outcomes and changes in power relations in society cannot be assumed. Therefore, the criteria used to evaluate involvement practice need to be determined by the rationale for involvement, with different criteria for normative and substantive involvement focused on different desired outcomes.

Understanding the rationale for involvement is therefore a key factor in judgements about involvement practice. This conceptual issue is central to this thesis because the rationale

provides the basis for evaluation, and supports the linking of purposes and aims of involvement to outcomes, and the evaluation of outcomes. Lack of clarity about purpose therefore is a fundamental problem for understanding and evaluating involvement.

The different rationales for involvement need to be related more effectively to understanding who should be involved, and questions of legitimacy and representation. Distinguishing between different publics (Michael 2009; Braun and Schultz 2010) helps to address questions of who should be involved. Distinguishing the interests of the general public from the interests of the affected public (Harrison, Dowswell and Milewa 2002; Coulter 2006) is also important because the NHS needs to address and balance both. Linking these distinctions to different purposes of involvement has the potential to support better planning, practice and evaluation.

The next section describes a theoretical concern in the literature about the potential of the affected public to bring a different perspective to involvement (Abelson *et al.* 2003, Michael 2009) and whether or not such experiential expertise amounts to a distinct rationale.

## **2.7 The contribution of experiential expertise**

Involvement contributions by the affected public are dependent on having an identifiable stake in particular issues or programmes of research, based on local knowledge, experience or an internal condition, Michael (2009). Having relevant knowledge and personal experience is also described as having experiential expertise or lay knowledge, which has been described as a source of authentic and legitimate involvement in section 2.4 (Michael 2009; Braun and Schultz 2010).

Involvement legitimised by experiential expertise has been described as drawing on a different rationale for involvement. Beresford (2003; 2013) identifies an epistemological rationale for involvement in research, arguing that the shorter the distance between direct experience and interpretation, the less distorted, inaccurate and damaging resulting knowledge will be. He challenges positivist views of research, which emphasise the need for research which is neutral, unbiased and distant from its subject, as devaluing lay knowledge. Martin (2008a) also distinguishes between a democratic rationale and contributions based on an epistemic rationale, and Boote, Baird and Beecroft (2010) similarly describe this rationale as distinct from the substantive rationale.

However, the inclusion of lay knowledge is also connected to the normative rationale. Popay and Williams (1996) see lay knowledge as highly critical and sceptical of science, and as a form of dissent, because it questions the given rules of those in power and challenges established

ways of thinking and knowing. Here science is an elite occupation, based on dominant epistemological assumptions about objective and generalisable truth, and critical theorists challenge the demarcation of science from non-science, arguing that it is also a social and political activity. Popay and Williams (1996) argue that professional expertise should be devalued and for a more egalitarian perspective on the contribution of different forms of knowledge. However, while some align experiential expertise with radical constructions of involvement that challenge established epistemology others take a different view. Caron-Flinterman, Broerse and Bunders (2005) and Elberse *et al.* (2010) see experiential expertise as complementing the scientific knowledge of experts, and the outcomes of involvement desired by the NIHR (2013) also suggest that expert and experiential knowledge can be productively combined.

The concept of lay knowledge is problematised by Shaw (2002), who argues that the idea of a laity with separate and distinctive beliefs from expert knowledge systems is a distortion. He describes a process of lay respondents internalising medical or professional constructions of the world. Drawing on Foucault, institutionalised discourses are sites of power and discipline, so power is more than a hierarchical structure, shaping social processes through which actors act in and shape their social worlds. Medical discourse is, therefore, a collaborative process involving both professionals and patients; in searching for meaning patients often adopt professionals' explanations of health and illness and to do so is 'common sense'. Adopting expert systems of knowledge enables patients to communicate with health professionals and present their case in a better light. Shaw (2002) suggests that no one in western society is unaware of professional explanations and that people routinely orient their perceptions of life around such rationalities. Such ideas undermine the more radical view of lay knowledge, because it is seen to be infused with established ways of thinking and power relations.

Sociological arguments valorising the radical potential of lay knowledge are also challenged by Prior (2003) who describes limits to lay knowledge in health and medicine, and reassesses what the public can offer to a democratised and customer sensitive system of health care, arguing that the concept of the lay-expert is an oxymoron. While laypeople have experiences of illness and diseases, and knowledge and information about their bodies and how they react to medication, they are not skilled in the diagnosis and management of illness. Prior (2003) argues that the virtues of expertise should be recognised, and that the use of technical knowledge should not be confused with the worthy political aim of ensuring involvement and consultation of the public in all matters to do with medicine.

However, Martin (2008a) argues that there is more to lay knowledge than Prior (2003) claims. Patients have sophisticated understandings and embodied insight distinct from clinical apprehensions, and are able to competently assess information from multiple sources. He finds that experience of disease prompts a desire to acquire detailed technical knowledge in some patients, bringing out willingness and ability to become an expert in ways which combine experiential dimensions with conventional scientific knowledge to develop a new positioned perspective. However, such processes can also be described as professionalisation (Thompson *et al.* 2012) leading to the loss of legitimacy.

Questions about the status of lay knowledge and its relationship to expert knowledge connect to deep problems, Hacking (1999) describes fears of relativism, where, if any opinion is as good as any other, this leads to many problems, including undermining the basis of knowledge. Collins and Evans (2002, 2007) respond to these problems of understanding the basis of knowledge and expertise, arguing that the problem of the legitimacy of science has been replaced by the 'problem of extension', a tendency to dissolve the boundary between experts and the public so that there are no longer any grounds for limiting the indefinite extension of technical decision making rights. Collins and Evans (2002) propose a normative theory of expertise with implications for involvement, where the affected public are experience-based experts. They distinguish between three levels of expertise, at the most basic where the public have no expertise at all and are unable to understand professionals. An intermediate level of interactional expertise is where members of the public have developed knowledge that enables them to interact meaningfully with professionals, and at the highest level some members of the public have developed contributory expertise in a specific domain, meaning that they can contribute new knowledge (Boivin *et al.* 2014).

Collins and Evans (2002) distinguish between political and technical domains of decision making, in the technical domain they argue contributions should be based on expertise, while political decision making remains a democratic process. Dyer (2004) has explored the implications of these ideas for involvement, asking which kinds of questions should be settled in the political domain, and which should be considered in the technical domain of scientific and medical experts, and she suggests that framing issues in this way raised theoretical problems about whether political rights and expertise (or power and knowledge) can be disentangled.

The focus on expertise questions the kind of contributions that are being made by the public, specifically between technical (knowledge based) and normative (value based) contributions. Both Dyer (2004) and Martin (2008a) argue that policy makers value involvement as source of

technocratic input on the basis of extending contributory rights to experiential expertise, they also agree that it is difficult to distinguish normative from technical contributions. However, the status of such expertise as a basis for involvement is contested. Martin (2008a) reports an 'assault' on the distinctiveness of contributions from uncertified experts on the basis of experiential expertise from constructivist academics, including Wynne (2003) and Irwin (2004), because any separation of technical and political questions is not viable since the idea of purely scientific questions endorses the powerful to define and delimit what science is. A second assault on experiential expertise is from those who accept the epistemic superiority of scientific over non-scientific understandings.

### **2.7.1 Discussion**

This section identifies that questions about the contribution of experiential expertise is a theoretical issue of importance to involvement. This is of particular significance in involvement in health research because this domain is a site for the production of expert knowledge, and involvement contributions are often sought from the affected public who are understood as having relevant expertise. It is helpful to clarify that the nature of contributions in involvement are both technical and normative.

However, the nature of lay knowledge is contested; some claim that it is distinct, and a form of dissent that provides a basis for radical challenge to dominant epistemologies (Popay and Williams 1996) and that more emphasis on lay knowledge would lead to the production of better knowledge (Beresford 2013). Others argue that lay knowledge can amount to contributory expertise (Collins and Evans 2002) and expertise which combines experiential dimensions with scientific knowledge in a positioned perspective (Martin 2008a). Such perspectives suggest that acquiring the skill and knowledge to interact meaningfully with professionals should be positively valued, not as process which undermines the legitimacy of experiential expertise (Thompson *et al.* 2012).

Others contend that members of the public internalise, adopt and commonly use medical and professional constructions of the world (Shaw 2002) so lay knowledge is not distinct, and Prior (2003) argues that lay knowledge is limited. The arguments in section 2.4.3, that those involved might be co-opted by involvement processes (Abelson *et al.* 2003) or socialised by acquiring training and information (Ives, Damery and Redwood 2012), position lay knowledge as fragile and easily obliterated by dominant interests.

Nor is there consensus as to whether experiential expertise should be understood a separate rationale for involvement based on technical contributions. Both normative and substantive



rationales also draw on the concept of lay knowledge, and these connections are reinforced by those who argue it is difficult to distinguish technical from normative contributions (Dyer 2004, Martin 2008a), so the idea of a distinct rationale is not convincing.

While the level, durability and distinctness of experiential expertise are all contested with implications for the conceptualisation of involvement, the affected public are understood as making technical contributions based on embodied insight and local knowledge of services. While not distinct from professional expertise, such contributions nonetheless amount to a rich source of relevant knowledge. The association of the affected public with authenticity and legitimacy in section 2.4 supports the view that personal experience and knowledge adds value in involvement.

## **2.8 Importance of context for involvement**

There is consensus in the literature that the context of involvement is significant, but context is conceptualised in different ways. Some authors identify different domains of involvement, for example, Charles and DeMaio (1993) identify three: the treatment of individuals, service delivery and macro or system level decision making. Tritter and McCallum (2006) propose healthcare system, organisation, community and individual domains, later increased to five: treatment decisions, service development, evaluation of services, education and training of health professionals, and research (Tritter 2009). Gauvin *et al.* (2010) identify three domains for health technology assessments, policy, organisational and research. Here, the context of involvement is the range of domains in which it takes place.

Smith *et al.* (2008) describe contextual factors as even more distant from the practice of involvement. Consumerist involvement, changes in patient-professional relations, growing public concern and expectations about research, and changes in the way research is undertaken are identified; such factors reflect the high level context of involvement without distinguishing domains of involvement.

Other approaches have been developed with varying success; in healthcare decision making Abelson (2001) offers a framework for analysing contexts and their influences on both method and outcome of involvement with three sets of contextual influences acting either independently or in combination. Einsiedel (2002) links contextual factors to characteristics of the involvement issue, the culture of the sponsoring organisation (including leadership style, commitment and resources for involvement), and attributes of the decision being made. However, Abelson *et al.* (2007) argue that these ways of thinking about context do not provide guidance about which contexts are associated with which involvement outcomes. Following

empirical work, Abelson *et al.* (2007) developed the earlier framework (Abelson 2001) and propose five contextual factors: political, community, organisational, researcher-decision maker relationships and decision making. All are seen as affecting both involvement processes and outcome. They find that a generic involvement mechanism can be successfully implemented to some degree independent of context, but that context exerts fostering and inhibiting influences, and some aspects of context matter more than others. Gauvin *et al.* (2010) analyse involvement in health technology assessments and identify four key contextual factors which influence involvement: specific project characteristics, institutions (resources, mandate, accountability and networks), professional and organisational interests, and ideas (knowledge, values, beliefs and expectations). Thinking about contextual factors has therefore been developed, but it is not obvious that the contextual factors identified in these domains would be transferrable to research.

In involvement in research Staley (2009) finds that the impact of involvement is highly context specific. This is confirmed by Brett *et al.* (2010), who describe context as whether or not the right conditions are in place for involvement in research, where context is distinguished from the processes of involvement which are more specific factors relating to the way that involvement is carried out. Context is described as the setting for involvement and the atmosphere/attitude in which it is conducted. However, Brett *et al.* (2010) do not separate context factors from processes of involvement, presenting both together as the architecture of involvement.

Staley *et al.* (2012) identify the need to understand and test the links between context, mechanism and outcomes more effectively, and relate the absence of such linkage to limited findings about the impact of involvement. They argue for a methodological approach to developing understanding of context based on realist evaluation (Pawson 2013 and Pawson and Tilley 1997). One realist evaluation conducted by Evans *et al.* (2014) has produced a theory of involvement in which context factors are identified. This includes the field of research, described as assumptions, procedures and practices that distinguish one field of research from another, including the research design. Other factors are principal investigator leadership and belief in involvement, and/or whether or not there is an established culture of involvement. However, Ennis and Wykes (2013) identify a number of different contextual variables in studies on the NIHR's Mental Health Research Network portfolio. These are: study complexity, differences between primary clinical studies groups (for example, psychotic disorders and mood disorders), funding body, and study type. Popay and Collins (2014) do not identify specific contextual factors, but the elements of the PiiAF framework include a number

of factors related to research focus and study design. These authors have identified a number of contextual factors related to research environments, which differ from the factors proposed by Brett *et al.* (2010) which are more closely connected to processes of involvement.

### **2.8.1 Discussion**

Although the context of involvement is often understood in the literature as important, different factors are identified in different domains of involvement. While there are frameworks theorising contextual factors in involvement in healthcare decision making (Abelson 2001; Einsiedel 2002; Abelson *et al.* 2007) and health technology assessment (Gauvin *et al.* 2010) there is no evidence that they can be applied across involvement domains.

Some suggest that context factors are higher level, including broad environmental influences (Smith *et al.* 2008), while others identify factors closer to involvement practice (Brett *et al.* 2010). A range of contextual in the research domain have been identified (Ennis and Wykes 2013; Popay and Collins 2014; Evans *et al.* 2014), but they have not been synthesised. The use of realist evaluation has been proposed to develop understanding of links between context, mechanism and outcomes (Staley *et al.* 2012), but this approach has not been used extensively.

## **2.9 Importance of process for involvement**

Across the involvement literature there is consensus on the importance of how involvement is conducted, and the selection of involvement mechanisms, despite the calls for more emphasis on the outcomes of involvement described in section 2.5. This section reviews and synthesises factors identified as important involvement processes. This section builds on sections 2.3 and 2.4 which identified the importance of how involvement is constituted.

Abelson *et al.* (2003) report a focus in the literature on the design of involvement opportunities and different methods of participation. Involvement processes are confirmed as important in other fields, for example, a review of case studies of public participation in environmental decisions concludes that process matters (Beierle and Cayford 2002).

Questions about how to conduct involvement have generated a large volume of guidance. In health research examples include guidance on getting involved in research (Thorne, Purtell and Baxter 2001), survivor research (Faulkner 2004), payment for involvement in research (Scott 2004) young people in research (National Children's Bureau 2011). INVOLVE is a key source of guidance across many topics, for example, good practice in active involvement (INVOLVE 2007) training and support (INVOLVE 2010a), getting involved in research grant applications

(INVOLVE 2006a) or commissioning boards (INVOLVE 2006b). Much guidance looks in detail at specific issues; this section focuses on the identification of more generic process issues with broad applicability. Key involvement processes identified have been synthesised under a number of headings, with an emphasis on involvement in research.

### **2.9.1 Early involvement.**

A number of authors identify the importance of involvement early in the development of a project, for example, Rowe and Frewer (2000) suggest it should be as soon as value judgements become salient. Reviews of involvement in research (Brett *et al.* 2010; Shippee *et al.* 2013) also emphasise early involvement. INVOLVE (2012b) stresses the need to involve people in the identification and prioritisation of research topics, and the development of research questions. The benefits of involvement at these stages includes widening the set of topics considered in research and opening up new areas of research, alongside initiating new studies (Staley 2009). Caron-Flinterman, Broerse and Bunders (2005) describe nine examples where patients' experiential knowledge has been translated into ideas for research and McCormick *et al.* (2004) report how the focus of breast cancer research shifted to investigate environmental factors which were of public concern. Staley (2009) identifies nine case studies reporting impacts of early involvement on study design, including clarifying research questions and challenging researcher assumptions. Similarly, Brett *et al.* (2010) report nine cases of beneficial impacts of involvement in setting research agendas.

### **2.9.2 Good relationships and communication**

Abelson *et al.* (2003) identifies that communication is a guiding principle of involvement, and experienced citizens stress the importance of getting communication processes right above addressing other guiding principles (Abelson *et al.* 2004). Telford, Boote and Cooper (2004) and Brett *et al.* (2010) emphasise that researchers should respect the skills, knowledge and experience of research partners. Brett *et al.* (2010) report establishing good relationships as a key factor in the architecture of involvement in research, and good communication as a way to manage conflict and avoid isolation. Shippee *et al.* (2013) identify building reciprocal relationships as one of four key involvement processes and also emphasise a sense of equality between parties, and Evans *et al.* (2014) report that building relationships between researchers and research partners made a difference to involvement outcomes.

Providing feedback to research partners on the work they have done and project progress is another important communications issue. Hewlett *et al.* (2006) report that receiving early feedback from researchers is crucial in developing research partners' confidence. One of four key involvement processes proposed by Shippee *et al.* (2013) is the need for involvement to be

re-assessed over time and feedback provided, and Evans *et al.* (2014) also identify that feedback to research partners on their impact and value is important.

### **2.9.3 Provision of training, support and information**

The need for research partners to have access to training and support is emphasised by a number of authors, including the provision of relevant information. Telford, Boote and Cooper (2004) suggest training and support is a principle of successful involvement, indicators include assessment of research partner training needs, and mentors providing personal and technical support. Researchers having the necessary skills to conduct involvement and ensuring that their own training needs are met is another of their principles. Hewlett *et al.* (2006) report that support from the lead researcher is crucial to facilitate communication in meetings, alongside support from an experienced research partner. Training is seen as important to develop understanding of research processes and methods. Brett *et al.* (2010) identify the provision of training on research skills as a key factor, alongside training for researchers. They include the need to provide additional information about the disease or condition, and the provision of personal support and supervision. Wright *et al.* (2010) suggest that the nature of training is an appropriate appraisal criterion, including training for research partners and researchers where necessary. Other considerations include support needs, including peer supervision, and provision of adequate information about research tasks. Shippee *et al.* (2013) identify co-learning as a key involvement process, including opportunity to acquire research expertise and researcher training. Popay and Collins (2014) describe the availability of training and access to information as key practical issues which shape involvement.

These authors agree that involvement in research should be supported by provision of training and support, but the extent and nature of training needed is not identified. However, the need for training is questioned because it leads to professional socialisation (Ives, Damery and Redwood 2012), and Thompson *et al.* (2012) suggest that training undermines the credibility of experiential expertise, but Staley (2013) counters that people do not lose their lay perspectives as a result of training. While training and support have less emphasis in the domain of health system decision making, the provision of information is seen as important (Rowe and Frewer 2000), and within deliberative methods one of the four principles for the design of involvement is provision of information (Abelson *et al.* 2003).

The provision of training is a contested process in involvement in research but many authors argue it is a key process, but some criticise it for increasing professionalisation and undermining experiential perspectives. These differences of perceptions can be related to different rationales of involvement, for substantive involvement contributions are technical

and training is a good thing, but for normative involvement it undermines research partner capacity to take an adversarial involvement role.

#### **2.9.4 Resources/budget for involvement**

Another important involvement process is provision of resources and a budget for involvement. Rowe and Frewer (2000) identify resource availability, including people, material resources and time, and cost effectiveness/value for money as two of four key implementation criteria. Researchers budgeting appropriately for the costs of involvement is a principle of successful involvement in research (Telford, Boote and Cooper 2004), and indicators for this principle include application for funding for involvement, and research partners receiving indirect costs.

An appropriate budget for involvement, including time, expenses and costs of training is also a key part of the architecture of involvement identified by Brett *et al.* (2010), alongside a need for additional time to be allowed for involvement within a research study. Popay and Collins (2014) also confirm the importance of the level and type of resources available to support involvement, as well as the provision of payment and expenses for research partners, including travel and accommodation as needed.

While there is consensus about the need for resources for involvement, the payment of the public for their time is a vexed issue. While INVOLVE (2012c) promote payment those involved report a range of views (HealthTalkOnline 2014). Rickard and Purtell (2011) identify problems in accepting payments for those receiving benefits, pensions and tax entitlements, and suggest that pay is both an ethical and policy issue and that practice is extremely varied.

#### **2.9.5 Reporting of involvement**

The understanding of involvement is seen as weakened by poor reporting. Harrison, Dowswell and Milewa (2002) suggest that organisations should provide explanations and accounts of decisions taken to those involved. Telford, Boote and Cooper (2004) propose that a principle of successful involvement should be descriptions of involvement in research reports and publications, including clear acknowledgement and details of how research partners have been involved. They also propose a principle that research findings should be available to research partners and other relevant user groups and organisations in accessible language and formats.

Wright *et al.* (2010) also include the need for involvement in dissemination of research findings in their guidelines, including in writing of accessible publications, and being informed about how findings have been disseminated to research participants and other relevant groups.

Brett *et al.* (2010) identify two related factors: providing detailed information in reports and

publications about how involvement is conducted, and the need for a lay summary of the final report.

Significant work has been done to develop reporting requirements for involvement in research (Staniszewska *et al.* 2011b). A checklist has been developed and reviewed in a consensus process to consult experts on the appropriateness and feasibility of its use, with the aim of improving the evidence base. While many academics agree that involvement should be reported, it is not yet clear whether practitioners will respond.

### **2.9.6 Other factors identified by some authors**

A number of other process factors have been identified as important, but without such broad agreement. In involvement in agenda-setting, decision making and policy forming activities the need for clear procedures is highlighted. Rowe and Frewer (2000) suggest that structured decision making processes are a key implementation criterion for involvement and Abelson *et al.* (2003) propose that procedural rules should have careful attention when using deliberative methods. The importance of impartial facilitation, and transparency about how decisions are made, are also identified as important by these authors, suggesting that process factors may relate to particular domains of involvement.

Staley (2009) identifies a number of other process factors which influence the impact of involvement in research including involvement throughout a study and long-term involvement. Hewlett *et al.* (2006) find that facilitation by the principal investigator is important for the inclusion of research partners, particularly stressing the chairing of research meetings, and the importance of leadership has recently been emphasised by Evans *et al.* (2014), including senior leadership and having an identified lead for involvement activities.

In the domains of policy formation and service improvement there has been more emphasis on the effectiveness of different involvement mechanisms. Harrison, Dowswell and Milewa (2002) argue that evaluation of involvement should consider whether the mechanisms used were consistent with aims of involvement. Crawford, Rutter and Thelwall (2003) identify many different mechanisms of involvement in use in involvement to improve care in the NHS. Rowe and Frewer (2005) have developed a typology of involvement mechanisms, including more than 100 different mechanisms and terminological problems in how they are described. The sheer number of mechanisms they identify makes the task of evaluating the effectiveness of different mechanisms very lengthy, if not impossible. The absence of consideration of different involvement mechanisms in involvement in research is a gap in the literature.

Other process issues of importance, including the representativeness and legitimacy of those involved, were described in section 2.4. In addition, Rowe and Frewer (2000) propose that a descriptive representative sample of the population of the affected public should be an acceptance criterion for legitimate involvement in healthcare decision making.

### **2.9.7 Discussion**

There is consensus about the importance of how involvement is conducted despite a need to focus more on outcomes. This review has synthesised five key process issues which many authors identify as important across involvement domains; early involvement, good relationships and communication, provision of training, support and information, provision of resources and budget, and reporting of involvement. However, some authors contend that training is not desirable.

Clear decision making procedures, impartiality, transparency, and representation, have been identified as important in domains of policy forming, agenda setting and decision making. These domains are more oriented to the normative rationale in the sense that the focus of attention is on the formation or modification of policies that potentially affect many people, and making difficult decisions about provision of health services, both of which may need to be considered by more general publics and include both normative and technical considerations.

It seems that the domain of involvement determines the relevance of some processes, which suggests that other aspects of the context of involvement may have implications for the application of involvement processes; however, these interconnections are not currently well understood. In involvement in research the significance of involvement mechanisms has not been considered, this is a gap in the literature potentially affecting the evaluation of involvement practice.

### **2.10 Conceptualisation of involvement in research**

A number of authors argue that the conceptualisation of involvement needs improvement, alongside calls to develop a stronger evidence base. These issues have particular emphasis in involvement in research (Boote, Telford and Cooper 2002). Staniszewska *et al.* (2011a) synthesised issues from two systematic reviews (Brett *et al.* 2010 and Mockford *et al.* 2012), and identify a number of problems with evidence including limited conceptualisation, poor reporting of context and process, enormous variability in the way impact is reported, little focus on negative impacts, and little formal evaluation of the quality of involvement. These problems are compounded by issues with terminology, section 1.2.2 identified that the terminology is problematic in a number of ways, including the use of different terms to



describe the activity of involvement itself, and terminology in different domains being used to mean different things. It is also clear that there is no agreed definition of involvement (Rise *et al.* 2011) in the academic literature, although in involvement in research practice there is a widely used definition provided by INVOLVE (2012).

Previous sections of the literature review have identified important themes in the literature, which provide key components for involvement practice. They are the rationale for involvement alongside related aims and outcomes, consideration of who should be involved, the context in which involvement takes place, and involvement processes and mechanisms. In my view, in order to evaluate the quality of involvement practice effectively, all these components warrant attention. This section reviews models of involvement that address, or have been used extensively, in involvement in research. Conceptualisations are considered in relation to the key components identified in order to consider whether, and to what extent, they provide understandings of involvement that help to guide and evaluate involvement practice that would be helpful for my project.

The most influential way that involvement has been theorised in the literature is based on Arnstein (1969) and subsequent modifications of her model. Collins and Ison (2006) suggest that this theory remains a 'benchmark' metaphor for describing and evaluating involvement which frames discussions in many areas, including business ethics, development studies, health planning, public administration, urban development and child studies. Arnstein (1969) developed a ladder of citizen engagement with eight levels from bottom to top, see Table 3. Only in levels six to eight had citizens achieved any power, levels three to five were all degrees of tokenism and levels one and two were non-participation. In Arnstein's language, 'participation' is a categorical term for power, so involvement is essentially a power struggle between citizens and controlling organisations and institutions. In assessing Arnstein, Stewart (2013) aligns her with concern for society's 'have-nots', and a radical perspective on involvement, with a focus on power relations and decision making.

This model enables evaluation of the transfer of power based on steps in the ladder, with the assumption that quality involvement gives citizens decision making power. Many authors have adapted this hierarchical approach (Feingold 1977; Wilcox 1994; Burns, Hambleton and Hoggett 1994; Choguill 1996; Cornwall 1996). However, the number of levels is usually decreased which is criticised by Eyles and Litva (1998). One version of this hierarchy has been used extensively in research; Hanley *et al.* (2003) describe three levels, consultation, collaboration and user control which appeared until recently in NIHR research funding application forms.

Stewart (2013) suggests that when different hierarchical theories are mapped against each other the content of each 'level' is reasonably consistent even where labels differ. Such comparisons produce four levels (Stewart *et al.* 2012) at the lowest informing or communicating with no power, a second level of consultation with little power, a third level of partnership/participation/co-production/collaboration where there is some degree of power sharing, and a fourth level of citizen control. Stewart (2013) notes the loss of levels and the focus in the middle of the ladder, which dilutes Arnstein's (1969) highly critical account.

**Table 3: Ladder of citizen engagement**

8	Citizen control	Degrees of citizen power
7	Delegated power	
6	Partnership	
5	Placation	Degrees of tokenism
4	Consultation	
3	Informing	
2	Therapy	Non-participation
1	Manipulation	

Adapted from Arnstein (1969 p. 217)

These hierarchical theories are critiqued on various grounds, for example, Bishop and Davis (2002) focus on the assumed linear relationship between non-involvement and citizen control, and the implication that the 'problem' in involvement remains constant, which is at odds with the range of policy problems they analysed. Tritter (2009) is critical of the view that citizen control is the ideal form of involvement, and suggests that other factors like diversity of actors, the importance of process, the need for a systematic approach and feedback are lacking.

Despite such critiques, the hierarchical levels of involvement have been used extensively as components of models which classify involvement alongside other dimensions, for example, Charles and DeMaio (1993) adds two role perspectives (user and policy) and three domains. In involvement in research Oliver *et al.* (2008) developed a theory of involvement where four hierarchical levels (minimal, consultation, collaboration, lay control) are related to researchers' degree of engagement. They also include the involvement of individuals or groups, and who

initiated involvement. This model aims to support the coherent description of involvement, and Tritter (2009) has developed it to include other domains of involvement. Gauvin *et al.* (2010) theorised involvement in health technology assessment with three dimensions, the level of involvement, type of public and research domain, alongside four contextual issues. These authors retain eight levels of involvement (from no involvement to user-control), with six types of publics and domains of policy, organisation (including governing agencies) and research. These models focus on some of the other key components of involvement alongside decision making, including who should be involved, but use different sub-categories. The domain of involvement is considered, but they do not include process factors or outcomes of involvement. While such theories classify and describe involvement activities, it is not clear whether or how such frameworks support the improvement of involvement practice, and the key criterion for evaluation is level of involvement.

Telford, Boote and Cooper (2004) do not include reference to hierarchical levels of involvement in their eight principles and associated indicators of successful involvement in research; while not presented as model of involvement they clearly identify important factors for evaluation. The rationale for involvement is not included, but the first principle is that the role of research partners should be agreed, which implies some consideration of aims. Most elements are process factors, as described in section 2.9, but they include some involvement tasks; involvement in recruitment, feedback on study progress to study participants, and dissemination of findings to academic and non-academic audiences. This approach provides useful insight, but does not consider who should be involved, contextual factors, or outcomes of involvement. Hewlett *et al.* (2006) outline an approach to involvement identifying key factors which were: facilitation of inclusion and contributions; identification of projects, patients and roles; respect for contributions and confidentiality; support for communication and training. This approach addresses a number of key components, with some consideration of aims and who should be involved, alongside important involvement processes, however, it does not include consideration of the context of involvement or outcomes.

Critical appraisal criteria to assess the quality and impact of involvement in research are proposed by Wright *et al.* (2010). These criteria include both rationale and level of involvement, and consideration of the diversity of who has been involved. There are criteria relating to ethical and methodological considerations, alongside criteria focused on dissemination of findings. Evaluation of involvement includes impacts with a focus on the 'added-value' of involvement activity being demonstrated, alongside consideration of negative impacts. These appraisal criteria address many of the key components identified in this

review, and they provide a range of useful questions to consider for evaluation, but they do not consider the context of involvement, or consideration of different mechanisms.

Based on their systematic review Brett *et al.* (2010) conceptualise the impact of involvement as a product of both context and process in an architectural framework. Three hierarchical levels of involvement are included as process descriptors or approaches to involvement. They identified 17 factors, but do not distinguish between contextual and process factors, although context is linked to whether the right conditions for involvement are in place, with examples given of funding, policy and attitude. Many of these factors have been described in sections 2.8 and 2.9, but they also include four involvement tasks; involvement in developing research documentation, in recruitment, data collection and analysis. This framework links some of the key components of involvement together, although there is no consideration of who is involved. However, the absence of consideration of rationale and of links between rationale (and related tasks) and outcome limits the potential of this framework for evaluation.

Barber (2014) has developed a later version of this approach where context includes many practical, conceptual and interpersonal issues, for example, political context, type of organisation, resources for involvement, concept of involvement and quality of working relationships. The type of public involved is a second part of the framework, including specific attributes of individuals. Details of the involvement tasks in research activities are the third element. These three elements are then considered in relation to impact issues, with implementation of research findings feeding back into the wider context. Barber's (2014) model does include many key components, but the context of involvement covers a wide range of complex issues which makes this part of the framework unhelpful in distinguishing key issues for consideration.

Morrow *et al.* (2010) propose a model for quality service user involvement in research which drew on theoretical perspectives of the meaning of power and empowerment. This model assesses quality in relation to personal factors alongside power issues within the social structures of research, so the quality of involvement emerges from interplay of personal factors and prevailing research contexts. This model uses a broader understanding of power and empowerment to evaluate involvement than decision making power, however, while the measure supports reflection on involvement it is only explores research partner perceptions. This model provides a way of evaluating empowerment with a focus on impacts on research partners. This model provides an interesting way of assessing quality, but it does not consider the whole range of key components important for evaluation.

Gibson, Britten and Lynch (2012) offer a four-dimensional framework for an emancipatory concept of involvement in research focusing on the knowledge spaces in which involvement takes place. They draw on Habermas (1987) for one dimension; a continuum between instrumental and expressive action, where more expressive spaces are seen as supporting expression of user perspectives and lay knowledge rather than the domination and distortion of the life-world in more instrumental spaces. Frazer (1997) provides a second continuum between strong and weak publics, where a strong public has the ability to influence decision making. The third continuum, from monist to pluralist, draws on Bourdieu's thinking about the struggle to appropriate forms of capital, where users from dominant groups with access to mainstream forms of capital would be favoured, with discursive assimilation a condition for involvement. Therefore, any unitary system of involvement is unlikely to facilitate diverse involvement, so more pluralistic and varied initiatives are needed to support people with less capital to participate in different ways. A fourth dimension is a spectrum between a tendency towards conservatism, including valuing existing structures and their predictability, and change which embraces innovation. This is a complex framework which develops understanding of emancipatory involvement. Both this theory and the one developed by Morrow *et al.* (2010) are oriented more to evaluation of issues considered important in the normative rationale of involvement. They focus on the evaluation of involvement processes, and provide different ways of thinking about the context of involvement, but neither addresses the outcomes of involvement on research.

Two models have been developed based on Collins and Evans (2002) theories of expertise. Dyer (2004) identifies four models of involvement – experiential-expert, non-certified expert, extra-scientific, and scientifically engaged - where different kinds of public contributions based on expertise validated different levels and kinds of involvement. This theory is complex and the implications are unclear. Stewart and Liabo (2012) argue against the downgrading of clinical and academic expertise implied by hierarchical theories based on Arnstein (1969), and propose a model of involvement in research where research quality and relevance are optimised when patient expertise is integrated with researchers' and policy makers' expertise. They apply Rowe and Frewer's (2005) conceptualisation of the flow of information in involvement alongside different kinds of expertise within the research cycle. Experiential knowledge is linked to problem identification and prioritisation, researcher expertise to the conduct of research, and policy maker knowledge to the implementation of findings. This model situates involvement within a technical process where the need for researcher, practitioner and policy maker expertise is legitimate, and where experiential knowledge adds to other forms of expertise. While this theory takes a new approach, there is no consideration

of the context of involvement, involvement processes or outcomes, and involvement is restricted to contributing to one phase of the research cycle.

Shippee *et al.* (2013) provide a two part framework to conceptualise involvement in research, part one includes four involvement processes (patient and service user initiation, building reciprocal relationships, co-learning/re-assessment and feedback) which have consecutive feedback loops of mutual influence. Part two reproduces three versions of hierarchical theories (Oliver *et al.* 2008; Hall 2009; Happell and Roper 2007) alongside phases of involvement throughout the research cycle. This framework does not consider the rationale for involvement, and there is no consideration of the context and outcomes of involvement. Identifying all phases of research as sites for involvement does not support the understanding of what involvement tasks might be addressed, and there is limited consideration of who should be involved. This is a classificatory theory which provides a structure for reporting and indexing involvement, but it is not clear how different elements of the framework relate to each other, or what they mean for evaluation.

The PiiAF framework (Popay and Collins 2014) has been described in section 2.5. It conceptualises involvement with five key elements: values associated with involvement in research, approach (including levels, mechanisms of involvement and involvement activities), research focus and study design, practical issues and impacts. The emphasis on values provides some consideration of rationale, processes of involvement are included as practicalities, alongside the importance of both contextual factors and outcomes. However, there less explicit emphasis on who should be involved.

### **2.10.1 Discussion**

In this section conceptualisations of involvement in research have been reviewed in relation to the key components of involvement identified in prior sections of the literature review, and the potential for such theories to underpin the evaluation of involvement has been considered. The most significant model was developed by Arnstein (1969) who provides levels of involvement to assess citizens' decision making power. These ideas have been adapted and used as a key element in theories of involvement by other writers, and they continue to be used in many contemporary theories of involvement in research. However, the variation in terminology and number of levels decreases the capacity of these hierarchical theories to provide comparable assessments of citizens' decision making power.

Theories of involvement based on hierarchical levels focus on who makes decisions, not the content of decisions made, which emphasises involvement (and power) processes rather than

impacts of involvement. However, the transfer of power is a key aim of involvement in the normative rationale, and modification of power relations is a desirable outcome of involvement. All hierarchical theories derived from Arnstein (1969) by implication use decision making as the evaluative criterion, reflecting a view of power premised on conceptualisations of agency and causality which Clegg (1989) describes as one-dimensional and limited, and in particular ignoring the structural face of power. Nor is it clear that decision making power is necessarily the right criterion to assess changes in democracy or social justice; it seems rather a crude reduction of such complex concepts. Morrow *et al.* (2010) and Gibson, Britten and Lynch (2012) share a conception of involvement as an activity intended to address social justice and power relations, and they provide alternative conceptualisations of power within their theories of involvement focused on empowerment and emancipation respectively.

Such theories address the normative rationale rather than substantive outcomes of involvement. The continued use of hierarchical levels of involvement in models of involvement in research is somewhat surprising given the orientation of NIHR policies (NIHR 2013) to the substantive rationale, and strong focus on the impacts of involvement by many influential writers (Boote, Telford and Cooper 2002; Staley 2009; Brett *et al.* 2010; Wright *et al.* 2010; Popay and Collins 2014). This might be understood as endorsement of the normative rationale and the need for involvement to deliver changes in power relations in research. However, levels of involvement have been used descriptively in some theories, without the implication that lower levels are inadequate, which questions authors' commitment to the transfer of decision making power as a key evaluative criterion.

Models of involvement reviewed in this section provide a range of different ways of conceptualising involvement in research. Many of these theories do not address some or many of the key components of involvement identified in this chapter, and nor do they often refer to, or build on, each other. Most have not been tested, so there is little evidence of their applicability in practice, their benefit for evaluating involvement or of their relative strengths and weaknesses. Some of the components, like the context of involvement, are included in theories but without any agreement about the meaning or constituents of the concept. Therefore, while there are a number of theories of involvement in research, there is no consensus about how it should be conceptualised with significant negative implications for evaluation. However, awareness of the range of approaches is helpful for my project, and while some models do not cover all components they still provide helpful perspectives for consideration, for example, the principles and indicators of successful involvement provided by Telford, Boote and Cooper (2004). The most comprehensive frameworks are provided by

Wright *et al.* (2010), Barber (2014) and Popay and Collins (2014) so these models provide the strongest basis for further conceptual development.

## 2.11 Conclusion

My thesis investigates the gap between theory and practice in public involvement in research so the literature review is oriented to identifying key critiques in the literature in order to understand what, how, and why practice fails to deliver. The review explores on what basis evaluative judgements about practice are made, and identifies significant themes and theories of importance to involvement. This chapter has reviewed how critiques of practice, key themes in the literature, and theories of involvement might inform the understanding and evaluation of involvement practice in my case studies.

Involvement practice is critiqued as a technology of legitimation (Harrison and Mort 1998) and as a market driven consumerist approach (Harrison, Dowswell and Milewa 2002; Beresford 2002; Martin 2008a; Smith *et al.* 2008; Tritter 2009; Gibson, Britten and Lynch 2012). Involvement practice is also understood as being constituted in ways that limits the scope of involvement activity by controlling the agenda and how involvement is conducted (Harrison and Mort 1998; Barnes *et al.* 2003; Braun and Schultz 2010). These critiques of involvement deployed to sustain existing power relations, and support managerial and institutional aims are based on normative understandings of legitimate involvement, where the legitimate purposes are to promote democracy and social justice and change social relations. While valid, such critiques evaluate involvement based on one rationale and, by implication, other potential aims of involvement are dismissed.

The literature review identifies significant interest in who is involved. There is consensus that more diverse involvement is desirable (Church *et al.* 2002; Martin 2008b; Robinson, Newton and Dawson 2012; INVOLVE 2012c), but professional control over who takes part is critiqued by Barnes *et al.* (2003) and Braun and Schultz (2010). The basis of legitimate contributions is contested, some value the politically active (Williams and Popay 1994; Epstein 1995; McCormick *et al.* 2004) while others suggest that involvement should avoid capture by pressure groups, with a focus on 'ordinary' people and disinterested citizens (Irwin 2006; Davies, Wetherell and Barnett 2006; Evans and Plows 2007; Learmonth, Martin and Warwick 2009). Others argue that citizenship should be embodied, and draw on experiential expertise (Barnes 2008; Martin 2012; Lehoux, Daudelin and Abelson 2012). Many express concern about whether those involved are representative (Crawford, Rutter and Thelwall 2003; Barnes, Newman and Sullivan 2004; and Martin 2008b), but the meaning of the concept in



involvement is not agreed (Litva *et al.* 2002; Crawford, Rutter and Thelwall 2003; Contandriopoulos 2004; Martin 2008a; Robinson, Newton and Dawson 2012).

Different conceptualisations of the public are identified, some distinguish different interests (Charles and DeMaio 1993; Harrison, Dowswell and Milewa 2002; Coulter 2006), while others differentiate between more general publics and particular or affected publics (Michael 2009; Braun and Schultz 2010). Challenges to the legitimacy of more general publics are connected to representativeness while the affected public is challenged on the basis of incorporation, co-optation, and professionalisation (Abelson *et al.* 2003; Michael 2009; Thompson *et al.* 2012; Ives, Damery and Redwood 2012). However, others value acquisition of additional knowledge and skill (Beresford and Campbell 1994; Epstein 1995; McCormick *et al.* 2004). The legitimacy of those involved is open to challenge from many directions, with significant capacity to undermine the value of contributions. Such diverse views provide no coherent basis for evaluating who is involved, so these questions can only be addressed by consideration of who should be involved in specific situations for specific involvement roles.

Another key critique identifies insufficient attention on the outcomes of involvement. Desired outcomes include impacts on policy, treatments and care, research and health (Rowe and Frewer 2000; Abelson *et al.* 2003; Crawford, Rutter and Thelwall 2003; Simces and Associates 2003; Staley 2009; Brett *et al.* 2010; Wright *et al.* 2010). A range of impact factors in involvement in research have been identified, but the feasibility of assessing outcomes on research is questioned (Barber *et al.* 2011), and some authors continue to emphasise improving involvement and research processes rather than outcomes on research (Smith *et al.* 2008; Shippee *et al.* 2013). However, reviews have identified a range of impacts on research, research partners and researchers and other stakeholders (Smith *et al.* 2008; Staley 2009; Brett *et al.* 2010). In involvement in research authors categorise outcomes in similar ways (Staley 2009; Brett *et al.* 2010; Popay and Collins 2014) and Popay and Collins (2014) have developed a comprehensive framework which provides a detailed and in-depth process to assess impact. The review identifies a significant gap between the current approaches to identifying outcomes and the kinds of impacts identified, and the desire to identify impacts on research, health policies, services, treatments and health. In addition, the desirable outcomes identified in policy and the literature in section 2.5 contrast with critiques of involvement practice which do not focus on democracy and social justice identified in section 2.3. This divergence draws attention to the need to relate the purposes of involvement to desired outcomes.

While some authors argue that democracy and social justice are the legitimate aims of involvement, others suggest that the purpose of involvement is not agreed and that it might be intended to improve health outcomes, service delivery, patient experiences, policies, education, or individuals (Cayton 2004; Bochel *et al.* 2008; Forbat, Hubbard and Kearney 2009; Stewart 2013). Therefore, the purpose of involvement in health and social care cannot only be aligned with normative understandings of involvement, and the failure of involvement to deliver on democracy and social justice cannot be understood as an over-arching failure, because involvement may have been undertaken with other purposes in mind.

The normative rationale is concerned with participatory democracy, and improving governance and accountability in the NHS (Harrison, Dowswell and Milewa 2002; Newman *et al.* 2004; Tritter and McCallum 2006). In addition, this rationale values social activism, civil and human rights and redistribution of power in society (Arnstein 1969; Harrison, Dowswell and Milewa 2002; Beresford 2010). Such involvement seeks to address a broad range of political concerns and legitimisation crises (Newman *et al.* 2004; Martin 2008a; Gibson, Britten and Lynch 2012). This rationale underpins the desirability of radical and partisan publics who can challenge those in power; problems of incorporation and professionalisation of those involved also assume legitimate involvement is an adversarial process where partnership working is suspect because 'public' and 'professional' interests cannot be shared, and collaboration serves dominant interests. However, there is evidence that those involved do not necessarily want political or decision making responsibility (Litva *et al.* 2002; Litva *et al.* 2009).

A substantive, or consequentialist, rationale for involvement is identified (Caron-Flinterman *et al.* 2006; Oliver *et al.* 2008; Elberse *et al.* 2010; Thompson *et al.* 2014), where contributions are oriented to the outcomes of involvement. Recognition of this rationale provides an alternative basis for the evaluation of involvement, which allows shared interests and where partnership and collaboration to improve substantive outcomes can be of positive benefit. While a focus on outcomes and impacts includes outcomes for research partners and researchers which can be associated with the normative rationale, the main focus of many authors who emphasise impacts is on substantive outcomes on research, treatment, care and health, not changes to political and social relations. The literature review has identified a key tension between the desirability of normative and substantive outcomes for involvement, with important implications for the evaluation of involvement that have not previously been explored or understood.

An emerging theoretical concern relates to the status of experiential expertise and what is being contributed, which is of particular significance in health research because this domain is

a site for the production of expert knowledge. Contributions are understood as both technical (knowledge based) and normative (value based) but difficult to distinguish (Dyer 2004; Martin 2008a). The nature of experiential expertise is contested, some claim it can underpin radical challenge to dominant epistemologies and improve the kind of knowledge produced (Popay and Williams 1996; Beresford 2013), others endorse the potential for high levels of relevant expertise (Collins and Evans 2002; Martin 2008a) with the implication that additional skill and knowledge are of value. However, others contend it is limited and not distinguishable from expert knowledge (Shaw 2002; Prior 2003), and arguments of co-option and professional socialisation position lay knowledge as fragile and easily obliterated by dominant interests.

Involvement based on experiential expertise has been identified by some as a separate rationale for involvement (Beresford 2003 and 2013; Martin 2008a; Boote, Baird and Beecroft 2010). However, lay knowledge has also been connected to the normative rationale, (Popay and Williams 1996) and the substantive rationale (Elberse *et al.* 2010). In section 2.4, the affected public has been seen to gain legitimacy from located knowledge which provides a basis for acceptance as authentic contributors (Michael 2009; Braun and Schultz 2010), and there are difficulties distinguishing technical from normative contributions. Such issues make the idea of a distinct epistemic rationale unconvincing.

There is consensus that context is a key component of public involvement in research, and that it will exert facilitative or constraining influences on involvement practice and outcomes, but there are different understandings of this concept. Some distinguish different domains of involvement (Charles and DeMaio 1993; Tritter and McCallum 2006; Tritter 2009; Gauvin 2010) or broad influences like consumerism (Smith *et al.* 2010). A range of context factors relating to the research environment are identified (Ennis and Wykes 2013; Evans *et al.* 2014; Popay and Collins 2014), and factors closer to involvement practice (Brett *et al.* 2010; Evans *et al.* 2014). While there are frameworks theorising contextual factors in involvement in healthcare decision making (Abelson 2001; Einsiedel 2002; Abelson *et al.* 2007) and health technology assessment (Gauvin *et al.* 2010) there is no evidence that this work can be applied across involvement domains. Drawing on Abelson *et al.* (2007) it seems likely that contextual factors at different levels need to be identified for involvement in research, including the wider environment or setting, in organisations, and at study level. Currently thinking about how to understand and evaluate context is under developed.

This review has synthesised five issues of importance in the conduct of involvement: early involvement; good relationships and communication; provision of training, support and information; provision of resources; and reporting of involvement. Most are understood as

generically desirable; however there is not agreement about whether training is desirable for all involvement roles (Ives, Damery and Redwood 2012; Thompson *et al.* 2012). Clear decision making procedures, impartiality, transparency, and representation are identified as important in the domains of policy forming, agenda setting and decision making (Rowe and Frewer 2000; Abelson *et al.* 2003). There is also more emphasis on the effectiveness of different involvement mechanisms in these domains (Harrison, Dowsell and Milewa 2002; Crawford, Rutter and Thelwall 2003; Rowe and Frewer 2005). The domain of involvement seems to determine the relevance of some involvement processes, and other aspects of the context of involvement may have implications for the application of involvement processes, but these links are not currently well understood. The absence of consideration of different involvement mechanisms in involvement in research is a gap in the literature.

The literature review identifies important themes in the literature which provide key components of involvement practice. They are the rationale for involvement alongside related aims and outcomes, consideration of who should be involved, the context in which involvement takes place, and involvement processes and mechanisms. In order to evaluate involvement practice effectively all these components warrant attention, and these findings are used to support the analysis of data in the project. In the final section conceptualisations of involvement in research have been reviewed in relation to the key components identified in order to consider whether, and to what extent, they provide understandings of involvement that help to guide and evaluate involvement practice that would support the conduct of my project.

A number of authors have emphasised that the conceptualisation of involvement needs improvement, alongside calls to develop a stronger evidence base. These issues have been particularly emphasised in involvement in research (Boote, Telford and Cooper 2002; Brett *et al.* 2010; Staniszewska *et al.* 2011a). Problems with conceptualisation are compounded by issues with terminology and definitions identified in section 1.2.2 (Boote, Telford and Cooper 2002; Beresford 2007; Rise *et al.* 2011; Stewart 2013).

The most influential conceptualisation was developed by Arnstein (1969) who provides levels of involvement to assess citizens' decision making power. This model addresses a key aim of normative involvement, transfer of power, with an emphasis on who makes decisions and involvement and power processes. However, this conceptualisation of power is limited (Clegg 1989) ignoring the structural face of power. Arnstein's (1969) ideas have been adapted and used as a key element in theories of involvement by other writers, and they continue to be used in many contemporary theories of involvement in research. By implication all such

theories use decision making as the evaluative criterion. Other authors have developed theories drawing on different conceptualisations of power, focused on empowerment and emancipation (Morrow *et al.* 2010; Gibson, Britten and Lynch 2012), but neither of these theories have yet been used extensively. These theories address the normative rather than substantive rationale of involvement.

The continued use of hierarchical levels of involvement in conceptualisations of involvement in research is somewhat surprising given the orientation of NIHR policies to the substantive rationale (NIHR 2013), and the desire to focus on outcomes for research as well as impacts on research partners (Boote, Telford and Cooper 2002; Staley 2009; Brett *et al.* 2010; Wright *et al.* 2010; Popay and Collins 2014). While this might indicate an orientation to the normative rationale, some authors use levels of involvement descriptively without the implication that lower levels are inadequate which makes their use more ambiguous.

The theories reviewed provide different ways of conceptualising involvement in research, but they do not necessarily address key components of involvement. Nor do they often refer to, or build on, each other. Most have not been robustly tested, so there is little evidence of their benefit for understanding and evaluating involvement, their relative strengths and weaknesses, or their applicability to practice. Some components, like the context of involvement, are included but without any agreement about meaning. However, awareness of the range of approaches is helpful for my project, and while some models do not cover all components they still provide helpful perspectives for consideration. The most comprehensive frameworks are provided by Wright *et al.* (2010), Barber (2014) and Popay and Collins (2014) so these models provide the strongest basis for further conceptual development.

The conceptual problems identified have significant negative implications for the systematic understanding and evaluation of involvement practice. A key issue is lack of consideration of the rationale for involvement because normative and substantive rationales value different kinds of outcomes, so should be evaluated by different criteria. Currently, elements of both normative and substantive rationales are combined in theories of involvement in research, generating tension about the relative desirability of different outcomes. While different rationales have been identified they are not necessarily distinct, many authors value outcomes desired by both normative and substantive involvement. This suggests that to be most useful, conceptualisation of involvement needs to address and accommodate different rationales.

The normative rationale values involvement as a tool to change power relations and improve society, with the assumption that the marginalised and socially excluded public are involved in

a power struggle. The substantive rationale values involvement as a tool to change research, policy, treatments, care and health, where public and professionals can work in partnership with shared interests. In normative involvement the desired outcomes focus on social justice and power relations, but in the substantive rationale consideration of power relations become process issues rather than outcomes. Failure to address the purpose and aims of involvement seriously undermines efforts to bridge the gap between theory and practice, and this understanding supports the conduct of this project by identifying a key area for attention. Increased appreciation of how different rationales and evaluative criteria underpin critiques of involvement practice, and identification of key components of involvement, provide important insight for the understanding and evaluation of involvement practice in my case studies.

## **Chapter 3: Philosophy of research, methodology and methods**

### **3.1 Introduction**

This chapter describes the philosophical orientation, methodology and methods used in my project. It is divided into three sections; section 3.2 describes my philosophical orientation which includes ontology, epistemology and theoretical perspective. Section 3.3 outlines the research methodology, and section 3.4 explains the methods used to collect data. In using these terms I am drawing on Crotty (1998) who identifies four elements of social research that inform one another: epistemology, theoretical perspective, research methodology and research methods. Following Crotty (1998) these terms are used as follows.

1. Epistemology, or theory of knowledge, describes the philosophical basis for deciding what kinds of knowledge are possible, and how to ensure they are adequate and legitimate. Ontology - the study of being - describes 'what is', the nature of existence and the structures of reality as such. Whilst ontology is distinct from epistemology they can and should be considered together Crotty (1998).
2. Theoretical perspective as the philosophical stance informing the methodology which provides a context for the research process, grounding its logic and criteria and including assumptions within the methodology.
3. Research methodology as the strategy and plan of action, the research design lying behind the choice and use of particular methods that link them to the desired outcome. For Crotty (1998) this is both a description of the methodology and an account of the rationale it provides for the choice of methods.
4. Research methods as concrete techniques or procedures that are used in research, the activities engaged in to gather and analyse the data. Crotty (1998) suggests that methods should be described in detail.

### **3.2 Philosophy of research**

The philosophy of research adopted was based on realism, abduction and reflexivity.

#### **3.2.1 Realism**

My position was based on realism, taking the view that there is a real world 'out there' but that it is not directly knowable in social research, and that while the world has been constructed by people over time the world confronted by an individual is already constructed.

*As particular individuals we confront a world most of which is not directly constructed by us, but is rather the complex outcome of earlier interactions between people and their structural contexts (Carter and New 2004 p. 7).*

Realism is based on a principle of naturalism, the view that society can be studied in the same way as nature in some respects (Carter and New 2004). Natural science can be seen as aiming to discover natural laws governing phenomena and although social relations cannot be reduced to unchanging generalisations in the form of laws, human behaviour is not inexplicable. Bhaskar (1989) argues that many interwoven dimensions of social life are roughly patterned rather than law-determined. Realism accommodates the fact that knowledge of the social world is necessarily perspectival and socially constructed by distinguishing clearly between our knowledge about the world, and the world which is the object of that knowledge (Carter and New 2004). Bhaskar (1989) and other realists describe our knowledge of the social world as the 'transitive' realm, and the world that is the object of knowledge as the 'intransitive' realm. Human knowledge is part of the transitive realm, the realm of concepts and theories which are historical, value-laden and 'situated', but the intransitive realm is not a product of our theories about it. As such social relations are part of the intransitive realm, and our knowledge about social relations can only be partial or provisional in nature and interpretive methods are needed to investigate the social world because of the need for meaning to be understood.

*Meaning has to be understood, it cannot be measured or counted, and hence there is always an interpretive or hermeneutic element in social science (Sayer 2000 p. 17).*

Carter and New (2004) provide a realist view of the debate on the relationship between human beings as the source of agency in the social world, and the structures of social relations that have been generated through interaction. This view is based on the ontological claim that structure and agency each possess distinct properties and powers in their own right. Social structures have a number of properties, for example anteriority, where language systems precede us and are pre-existing features of the world into which we are born. In addition, social structures are relatively enduring and have the power of enablement and constraint. Carter and New (2004) describe the properties of agents as including self-consciousness, reflexivity, intentionality, cognition and emotionality. As reflexive beings capable of sophisticated communications, people are able to formulate projects, develop plans, have ambitions and pursue interests. They can reflect upon and seek to alter or reinforce the social arrangements they encounter for the realisation of their own interests. The distinct properties and powers of structure and agency are seen as irreducible to each other. These ideas provide



theoretical support for seeking understanding about a real world based on situated knowledge, including navigating between social structures and agency.

With Carter and New (2004) I am committed to an explanatory model where the interplay of pre-existent structures, possessing causal powers and properties, and people, possessing distinctive causal powers and properties of their own, results in contingent yet explainable outcomes. The social contexts people inhabit provide them with “*directional guidance*” in terms of appropriate beliefs and courses of action (Archer 1995, p. 213), and people are influenced, though not determined, by their structural situations.

*People choose what they do, but they make their choices from a structurally and culturally generated range of options – which they do not choose* (Carter and New 2004 p. 3).

From this perspective, particular combinations of things, processes and practices can give rise to new or emergent properties, which are more than the sum of their constituent parts. In explaining the social world there is a need to move from the level of happenings and phenomena to be explained to that of the underlying mechanisms and structures which generate them (for example, sexism and racism). Bhaskar (1989) distinguishes between three ontological domains:

- the ‘actual’ comprising events, happenings, phenomena whether or not they are observed
- the ‘empirical’ as a subset of the ‘actual’
- the ‘real’ which included both the ‘actual’ and the ‘empirical’.

The ‘real’ also includes structures and mechanisms which may not be observed or observable, but are known by their effects. Carter and New (2004) suggest that this is just the beginning of the stratification of the enormously complex social world.

People in the social world are psycho-social subjects with a psyche formed in idiosyncratic personal circumstances with psychological characteristics and structures, as well as members of society shaped by social contexts and cultural norms. Clarke and Hoggett (2009) introduce the psycho-social subject to reflect their interest in emotion and affect. This subject position supports navigation between the individual and society, where people are subject to both inner and outer forces, both constructed and constructing, a power-using subject who is also subject to power (Clarke and Hoggett 2009). The psycho-social subject entails recognition that people are not necessarily rational and the importance of feelings.

I have taken the realist epistemological position that knowledge of the social world is necessarily perspectival and part of Bhaskar's (1989) transitive realm which is historical, value-laden and 'situated'. Because knowledge production takes place in the social world, and is constituted through lived experience in a particular time and place, it is socially constructed (Crotty 1998). Therefore, while accounts of experiences and meanings given by research participants are vital, they cannot generate a description of the world as it 'really' is. Accounts can never be complete in relation to the experiences to which they refer, and different people will provide different accounts of the same event, reflecting their different perspectives. However, the fact that accounts are ambiguous representations of experiences does not sever them wholly from reality and truth. Knowledge generated from such excerpts of social reality can be better or worse, where better means a richer, more textured and deeper account which acknowledges different perspectives and does not remove or ignore complexity and contradiction.

### **3.2.2 Abduction**

My research questions seek to understand and describe the phenomena of involvement in research from the perspectives of my participants, and initially I considered a research design based on induction, building theory from empirical data. However, as my thinking developed, induction seemed more problematic because all analysis must be grounded in concepts based on prior tacit or explicit understanding, whether or not this is formal theory. I also wanted to explore how existing ideas and theories of involvement might illuminate the data, and employ the data to develop thinking on the topic, which suggested a more deductive approach.

In explanatory models it is usual to distinguish between induction and deduction (Alvesson and Sköldbberg 2009), where an inductive approach proceeds from a number of single cases and assumes that a connection observed in all cases is generally valid, whereas a deductive approach proceeds from a general rule and asserts that the rule explains a single case. While these two models are usually regarded as exclusive alternatives, where induction has its point of departure in empirical data and deduction in theory, Alvesson and Sköldbberg (2009) argue that they need not be regarded as incompatible and could be combined in abduction. They suggest that abduction corresponds to Hanson's (1958) concept of 'retroduction', where facts are always theory-laden, and that people do not even 'see' single sense-data, but always interpreted data in a frame of reference. Hanson (1958) rejects both induction and deduction as models for research processes. Abduction allows the flexible and iterative combination of more inductive and deductive research processes which was important for my project;

Alvesson and Sköldbberg (2009) suggest that this approach is used in practice in many case study based research processes.

Abduction is a process of applying theory to empirical reality and adjusting theory in the light of empirical reality with a focus on underlying patterns (Alvesson and Sköldbberg 2009); like induction, abduction has its point of departure in empirical data, but it does not reject theoretical preconceptions and is in this respect closer to deduction. Analysis of facts can be combined with, or preceded by, studies of previous theory. Alternating between previous theory and empirical facts is endorsed, where both are successively reinterpreted in the light of each other. Abduction allowed me to shift my focus between empirical data and the use of ideas as different lenses through which to explore data.

The focus of the natural sciences is generalisation from induction but the exacting expectations which establish the credentials of such scientific knowledge are impossible in the social sciences (Thomas 2010). MacIntyre (1985) analyses the failure of theory resulting from the systematic unpredictability of the social world, and emphasises that a characteristic of the subjects of social science is "*pervasive unpredictability*" which render all projection in social life "*permanently vulnerable*" (MacIntyre 1985 p. 103). Therefore what can emerge from social science is more moderate, and Thomas (2010) argues that generalisation in social inquiry is always constrained to remain at the level of abduction rather than induction, but that abduction can produce theory in the form of phronesis, a concept which includes practical knowledge, craft knowledge and judgement, and a sense of tacit knowledge. Schram, Flyvbjerg and Landman (2013) promote phronetic social science, drawing on Aristotle's categorization of types of knowledge, where episteme is universal knowledge, techné is practical application of that knowledge in the form of technique, and phronesis is the practical wisdom that emerges from having an intimate familiarity of what works in particular settings and circumstances. They argue that social sciences cannot produce universal models because people are not amenable to being modelled by trans-contextual causal models. Instead social sciences are better adapted to provide contextually specific knowledge that can help people address the problems they confront in their lives. Research in the social sciences should enhance phronesis as part of a 'turn to practice' because what is interesting for understanding and praxis is what happens where particular circumstance and context meet general rules of governance and conduct (Schram, Flyvbjerg and Landman 2013). The development of such knowledge to support the practice of involvement was the aim of this project.

### 3.2.3 Analytical reflexivity

Earlier in this chapter reflexivity is described by Carter and New (2004) as one of the properties of people relevant to agency. However, reflexivity is a term used in a variety of ways in social research (Hammersley 2004). Section 3.3.3 below considers these different understandings of the term and describes my approach to this issue.

In addition, I have also used a reflexive methodology, drawing on the work of Alvesson and Sköldbberg (2009). Their approach was attractive because it includes analysis of data from different theoretical perspectives. In building a reflexive framework Alvesson and Sköldbberg (2009) consider four currents of methodology and philosophy of science, and suggest that research strategies can draw on these different ideas and use them in new contexts. The four orientations in their framework are:

- Empirical orientation in particular grounded theory.
- Hermeneutics and the primacy of interpretation.
- Critical theory and the awareness of the political-ideological character of research.
- Post-modernism and reflection on problems of representation and authority.

Alvesson and Sköldbberg (2009) argue that these different approaches are not incommensurable and that their use can support greater freedom and sophistication in empirical work. They describe their approach as having rather less focus on the empirical material and what data say about how things 'really are' and more on creativity and ideas. Using their framework means attending to different orientations without letting any one dominate, endorsing movement between different philosophical ideas and more empirically based elements in research. I did not use their framework in full as it is very complex; but I adapted their ideas and used different analytical perspectives to engage with data. The three perspectives I used were: empirical and more inductive, theoretical and more deductive, and a third with an explicit focus on power. Like Fereday and Muir-Cochrane (2006) I used a hybrid process of inductive and deductive analysis which integrated data-driven themes with theory-driven themes.

Data analysis addressed the more inductive perspective first to safeguard participants' subjective point of view, focussing on understanding their perceptions. I sought to set aside my preconceptions as far as possible and attended to participants' experiences, voices, words and meanings. Thematic analysis (Braun and Clarke 2006) was chosen because it is accessible and flexible, can offer a thick description, generate unanticipated insights, and highlight similarities and differences across the data set. This analysis focused on providing a thematic

description of data from the bottom up, which at this stage included data relating to three case studies. Data-driven codes were identified at a semantic level, within the explicit or surface meanings of the data (Braun and Clarke 2006) to describe and summarise patterns in the content.

The second phase of analysis drew on the literature review when a table of potential themes and codes were developed before data collection started based on the key components of involvement (see section 2.10). Themes developed in the more inductive analysis were reviewed in relation the themes identified from the literature. Comparing the two analytical structures identified that many themes were common to both, but led to reorganisation and refinement of themes and codes that were developed in phase 1. This process oriented the analysis more directly to the aim of the project to investigate the gap between theory and practice. Although power issues were identified as a significant issue in the literature, the first phase of analysis had identified few codes directly related to this topic. In the third phase of analysis data were reviewed with a focus on power.

Hammersley and Atkinson (2007) describe a tension between participant and analytic perspectives. On the one hand there is a need to understand the perspectives of the people being studied in order to explain their activities and describe them accurately; doing this requires researchers to suspend their own immediate inferences, common sense assumptions and theories as much as possible. However, at the same time there is also an emphasis on developing analytic understanding, which could differ from, or even conflict with, how the people studied saw their world. My strategy for navigating this tension was to undertake analysis of data from different perspectives in turn.

While the three analytical perspectives were addressed in order they were conceived as overlapping and interconnected and this was evident in the analytical structures that were generated. This approach supported and structured analysis of data, and provided a practical way of operationalising abduction. Further information is provided about the analytic process in section 4.6.

### **3.3 Qualitative methodology**

Based on realism, abduction and reflexivity, and in order to address my research questions, I chose a qualitative methodological approach. The methodology was chosen to support the investigation of what researchers and research partners were doing when they worked together in research, in order to understand their experiences of involvement and how they worked together, including consideration of the influence of contextual factors.

Green and Thorogood (2014) suggest the most basic characterisation of qualitative research relates to the aims of a study with a focus on questions of 'how', 'what' and 'why' of a phenomenon. Denzin and Lincoln (2008) offer a generic definition of qualitative research as a situated activity that locates the observer in the world, which consists of a set of interpretive material practices that make it visible by transforming the world into a series of representations. However, qualitative research is not a unified or well defined approach (Pope and Mays 2006; Silverman 2006); although it developed largely in anthropology and sociology it has been established in a range of disciplines which have affected its evolution (Avis 2005) and it can include a range of theoretical perspectives, for example, phenomenology, social constructionism, critical, feminist and participatory approaches (Green and Thorogood 2014). Nonetheless, qualitative research is often concerned with classification, answering questions about what a particular social phenomenon is, how it varies in different circumstances and why, and with the meanings that people attach to their experiences of the social world and how they make sense of the world (Pope and Mays 2006). The focus on meaning and understanding in qualitative research is emphasised by Green and Thorogood (2014) which entails the interpretation of social phenomena, where the researcher frequently has to question common sense and taken for granted assumptions, which Bauman (1990) refers to as 'defamiliarising'.

Qualitative research is also distinguished by studying people in their natural settings rather than in artificial or experimental ones (Green and Thorogood 2014), which Pope and Mays (2006) describe as a key strength. Denzin (1971) emphasises 'naturalism' as a defining aspect of distinctly qualitative research, with an empirical approach to studying the social world closely tied to the everyday routine lives of the people researched, aiming to understand their perspective and then reproduce participants' experiences, thoughts, and language in a rich and detailed description. Green and Thorogood (2014) reflect on the potential for people to behave differently when being studied, and point out that there is no 'untainted' research field accessible to qualitative researchers, whatever length of time they spend immersed in a particular setting to minimise their impact, where any act of observation will have an effect. The impact of social research on the field studied implies the need for a reflexive approach to qualitative research, where researchers subject their own research practice to the same critical analysis deployed to study their topic (Green and Thorogood 2014). For these authors reflexivity requires two levels of critical reflection, first situating research questions within a social and political context which makes particular kinds of questions legitimate and interesting, and secondly focusing on the role of the researcher in generating and analysing their data. This project includes reflection on the history and policy context of involvement in

research in section 1.2.1 and identifies key themes in the involvement literature which have influenced the research agenda in the field in chapter 2. Reflexivity in relation to my role as researcher is explored further in section 3.3.3.

Another feature of qualitative research identified by Green and Thorogood (2014) and Avis (2005) is that it requires flexible research strategies, which mean that research plans can be adapted in relation to early data collection and analysis where researchers are allowed to develop hunches and hypotheses, and test them, as the study progresses. In addition qualitative research often is characterised by the use of a range of methods including observation, interviews and documentary analysis (Pope and Mays 2006).

The qualitative methodology of this project was influenced by ethnography, in particular because of the need to understand the context of involvement in research and to observe involvement activities. Reeves, Kuper and Hodges (2008) have described ethnography as the study of social interactions, behaviours and perceptions that occur within groups, teams, organisations and communities, with a central aim to provide rich, holistic insights of people's views and actions, as well as the nature of the locations they inhabit, through the collection of detailed observation and interviews. Hammersley and Atkinson (2007) suggest that while ethnography has varied forms and a contested character, it has come to be understood as an integration of first hand empirical investigation and the theoretical and comparative interpretation of social organisation and culture. Ethnography has been endorsed for use in health research by Savage (2000), Lambert and McKeivitt (2002) and Huby *et al.* (2007).

### **3.3.1 The importance of context and observation**

In designing the project I wanted to observe involvement activities as well as collecting accounts of involvement, in order to support understanding of what researchers and research partners did when they worked together. This was particularly important because involvement is endorsed by government policy and research funding policies drive involvement activity whatever the values and attitudes of health researchers (see section 1.2). The potential tensions between policy and practice made a focus on the difference between what was said and what was done important in the data. In addition, the significance of context has been identified as important for involvement in research (see section 2.8), and observation would support the exploration of these influences.

I was influenced by ethnography because of its empirically based grasp of the context specific nature of social processes (Savage 2000; Lambert and McKeivitt 2002). Ethnographic research confirms the importance of observation because it aims to understand the social meanings and

activities of people in a given setting by close association with the setting (Brewer 2000), where knowledge is acquired from familiarity with the social world being studied, thus establishing the importance of field work. Burgess (1982) defines field work as studying real-life situations, observing people in the setting of interest and participating in their day to day activities. These ideas of how to develop understanding of social phenomena by becoming familiar with the social world of interest, including both observation and participation in the setting, shaped my stance in conducting observations. While these ideas are drawn from ethnography, Green and Thorogood (2009) suggest that observational methods are the 'gold standard' of qualitative methods because they provide direct access to what people do.

The observation of activities in qualitative research has been endorsed by other writers; Pope and Mays (2009) suggest that qualitative research needs to do more than taking talk at face value, and that observation is needed to see what people really do, not just what they say they do. Silverman (2005) emphasises the importance of collection of data in naturally occurring situations. Angrosino and Mays de Perez (2000) suggest that observations underpin all research methods, and describe a number of principles which include the decision to take part in a social setting.

These ideas underpinned my thinking about how to investigate the context and practices of involvement in the case studies; while the constraints of this project did not allow me to spend long periods alongside participants, seeking opportunities to observe involvement was an important part of my research design.

### **3.3.2 Case study approach**

My research necessarily focused on a few examples of involvement within the constraints of a doctoral project. In-depth focus on one or a few cases has been used by many researchers in involvement, for example, Boote, Baird and Sutton (2011) report on case examples of involvement in the design and conduct of clinical trials. Rabeharisoa (2006) conducted a socio-historical case study of collective mobilisation on muscular dystrophy in France, and Weiner (2009) reported on lay involvement and legitimacy within HEART UK.

Yin's (2009) approach to case study research describes empirical inquiry that investigates a contemporary phenomenon within its real-life context that is especially useful when the boundaries between phenomenon and context are not clearly evident. In the involvement literature such boundary problems are apparent, for example, Brett *et al.* (2010) do not distinguish between process factors and context factors in their systematic review. Yin (2009) identifies other technical characteristics of case studies, including more variables of interest



than data points, reliance on multiple sources of evidence, and as benefitting from development of theoretical propositions to guide data collection and analysis; all were relevant to my project.

Based on Yin's (2009) typology of case studies, I conducted a multiple case study, where the unit of analysis was involvement within a specified health research study. The case studies were incomplete because involvement (and research studies) had started prior to my data collection period, and continued afterwards; however, this was unavoidable given the time frame of my project in relation to the research study time frames.

Case studies are criticised because they do not support generalisability (Silverman 2006), but Yin (2009) argues that case studies are multiple experiments which support analytic generalisation, where previously developed theory is used as a basis for comparing the empirical results. Flyvbjerg (2006) suggests that case studies are especially well suited to producing context dependent knowledge, and agrees that some kinds of generalisations could be developed from them. The field of involvement has been described as conceptually under-developed (see section 2.10) and I wanted to employ the data to assess the potential benefits of theories of involvement to indicate fruitful areas for theoretical development, where applicability of ideas in different contexts could indicate the utility of different theories. Eisenhardt and Graebner (2007) support theory building from cases, however, my aim was not to build new theory using a grounded theory approach, but to consider the utility of ideas already described in the involvement literature in the light of empirical analysis.

### **3.3.3 Reflexivity**

Because researchers are part of the social world studied reflexivity is needed to consider the researcher's role in the creation of knowledge (Hammersley 2004; Green and Thorogood 2014). Finlay (2002) defines reflexivity in relation to the researcher's role as thoughtful, conscious self-awareness, and reflexive analysis in research as ongoing evaluation of subjective responses, dynamics between people, and the research process itself, with recognition of how knowledge is actively constructed. Different understandings of reflexivity and reflexive practice have been developed in relation to different theoretical approaches which make reflexivity challenging. While all approaches might generate insight they are acknowledged as time consuming and painful processes, which are difficult to report within academic word limits.

Berger (2015) suggests that reflexivity in practice includes monitoring the impact of researcher biases, beliefs and personal experiences on research, including a process of continual internal

dialogue and critical self-evaluation of researchers' positionality. It requires active acknowledgement that the researchers' position may affect the research process and outcomes (Bradbury-Jones 2007; Stronach *et al.* 2007), alongside recognition of situatedness and its' effect on the setting and research participants (Berger 2015). Relevant positioning includes personal characteristics, for example, gender, ethnicity, age, personal experiences, linguistic tradition, political and ideological stances and emotional responses to participants. I have made my position more visible in the thesis by providing biographical information, including some relevant personal characteristics, background and reflection on my experience of mental health problems and history of involvement in section 1.1 and Appendix 1. In addition, in section 4.8 I reflect further on my position.

My position in this project included having insider status in the sense of relevant experience of involvement including contributing as a research partner, prior relationships with researcher and research partner participants, and some status as a member of the national NIHR INVOLVE advisory group. While insider status is linked to having relevant knowledge for research which could improve ability to understanding implied content, and diminish the distance between researcher and participant (Berger 2015), a need to avoid imposing values, beliefs and perceptions arising from insider knowledge is also identified, and dangers of missing information assumed to be obvious by taking similarities for granted. These issues raise the question of how to use personal experience which offers positive potential to deepen understanding, and at the same time to avoid imposing a researcher's experience on participants (Pillow 2003). My aim was to draw on my own experiences in data collection primarily to guide my prompts and requests for clarification, and to check whether my own interpretations of experiences were similar or different to participant interpretations. I chose to disclose my status as a mental health service user and experienced research partner to all participants; while self-disclosure might help to 'level the playing field' in relation to power, it might also create feelings of comparison and competition for participants (Berger 2015), therefore the impact of self-disclosure was not predictable.

However, reflexivity is not without critics; Salzman (2002) points out that our own impressions as researchers cannot be privileged as authoritative, even under such an impressive label as 'reflexivity', and he questions whether general biographical characterisations, including gender, race and class, communicate much about the actual perspective of any particular individual because people do not conform to social stereotypes or cultural labels. He also points out that misleading others is one of the main psychological and social purposes of many declarations about the self. The dependence of reflexive accounting on self-reporting, realistic

self-awareness and honest disclosure are seen as rather naïve pre-Freudian ideas by Salzman (2002), who argues that such assumptions are unwarranted. Such views cast doubt on the reliability of reflexive accounts. However, while self-reporting may be problematic it was still important to provide information with as much integrity as possible, particularly given my prior experience of involvement, alongside established relationships and roles in involvement in research

### **3.4 Methods**

My data collection methods included observation, interviews, and collection and analysis of documents. They were complementary ways of creating a rich picture of involvement and of developing understanding in the context of research activities, and provided flexibility to tailor data collection over time and to suit individual case studies. Further information about how data were collected and analysed is provided in sections 4.5 and 4.6 in the next chapter.

#### **3.4.1 Observation**

Green and Thorogood (2009) provides a typology of observational methods from complete participant, where the researcher is a 'native' in the field they are observing to complete observer, where the researcher does not participate at all, for example, video or audio recording medical consultations. In between are the roles of observer-as-participant and participant-as-observer, where the balance of observation and participation shifted in emphasis, and my observations were informed by these two roles. Roles are classified as overt or covert Green and Thorogood (2009); my observational role was overt.

My observations were unstructured without predetermined headings. Observations were recorded in field notes and by audio-recording meetings. Writing of field notes was informed by Emerson, Fretz and Shaw (1995), who point out that while field notes describe experiences and observations, written descriptions do not correspond to a 'best' description. Description involves both perception and interpretation (and therefore some kind of tacit or explicit prior understanding or theory), and different descriptions of the same event are possible. Writing field notes involves reduction of the full experience of the social world to words that can be studied and thought about; writing field notes therefore changes things from passing events into an account (Emerson, Fretz and Shaw 1995), so clear distinctions between data and personal responses are misleading.

### 3.4.2 Interviews

While my research design included the need for observations, semi-structured interviews were also a key source of data. Green and Thorogood (2009) describe interviews as a particular kind of conversation geared to the researcher's needs, and semi-structured interviews as situations where the researcher set the agenda in terms of the topics covered, but interviewees responses determine the kind of information produced and the relative importance of topics. My interviews were semi-structured and allowed time for participants to develop their own accounts of the issues important to them; I allowed between 45 minutes and an hour. I sought to build relationships, trust and rapport, which included disclosing some personal information.

As well as providing understanding of the meanings of experiences interviews can be used to test research hypotheses. Pawson (1996) conceptualises research interviews as opportunities to share research theories where interviews are a process of education to enable critical comment on researchers' theories. This seemed likely to generate useful reflection, so where participants' contributions connected to emerging themes as the project developed I shared and discussed my ideas.

Interaction in research interviews produce data about beliefs, behaviour, and ways of classifying the world (Green and Thorogood 2009), and most people are familiar with the format and rules of engagement. The nature of the account given depends on the relationship between the researcher and interviewee. Social differences – race, class, socio-economic status, age and gender – have an impact on the data produced in complex ways (Green and Thorogood 2009).

Kvale (2006) encourages scepticism of trusting and empathic relationships in interviews, because they can elicit unguarded confidences for researchers' benefit. Such manipulative potential is often disregarded. The qualitative research interview entails hierarchical relationships with asymmetrical power distribution. Interviews are controlled in a number of ways:

- the interviewer asks the subject answers
- the conversation is a means to the researcher's ends
- the interviewer monopolises interpretation.

However, despite such power asymmetry interviewees can resist, for example, by not answering, deflecting questions, or talking about something else. Kvale (2006) suggests that while the use of power in interviews to produce knowledge can be valuable and legitimate, overlooking power dynamics can impair the validity of the knowledge constructed. These

ideas were an important reminder that rapport might be used manipulatively to increase disclosure and to guard against inappropriate intrusion.

The questions in my semi-structured interview were developed based on my research questions, informed by the first phase of the literature review and drafted separately for research partners and researchers; see Appendix 5 and Appendix 6. Questions were first drafted in response to a Research Ethics Committee request for an interview schedule. Topics included prior involvement experience, recruitment, involvement expectations and tasks, induction, support, training and payment, relationships and impact, with space to raise additional issues. Questions were adapted for individual participants and contexts, and as the project progressed.

### **3.4.3 Documentary analysis**

Documentary analysis was important because the product of research is reported in documents, and research is controlled by documents required in the research governance process, particularly within the NHS. The reporting of involvement in research is described as a significant problem (Staniszewska *et al.* 2011b), so I was interested in whether and to what extent involvement was documented and reported in the case studies.

Prior (2008) notes the relative neglect of text and documents in social research, despite their importance in the modern world. Bowen (2009) identifies a number of rationales for documentary analysis; as a means of triangulation to seek corroboration of other forms of evidence, in case study research, and as a standalone method for some forms of research. The value for case study research is described as immense, where documents can be a source of meaning, understanding and insight, and in particular provide important data on the context within which a participant operates. The rationale for including documentary analysis in this project was primarily to increase understanding of the context of involvement activities and to seek corroboration of evidence identified in other data collection methods. My approach to the analysis of documents is described in section 4.6.1.

### **3.4.4 Reflective diary**

I kept a reflective diary to record my ideas and feelings throughout the research process. Alaszewski (2006) defines a diary as a document created by an individual who maintains a regular, personal and contemporaneous record. Important characteristics are sequenced and dated entries, personal reflections, and that entries are made at the time or close to the time when events or activities occur so they are not distorted by problems of recall. Burgess (1981) advocates the use of a research diary to enable researcher reflexivity, with emphasis on their

role in the research process and implications of contact with participants; my diary included such reflections. Bloor and Wood (2006) recommend recording analytic and methodological memos to document working hypotheses and development of ideas, and I wrote analytic reflections in my diary and memos in Nvivo (QSR International 2010).

### **3.5 Conclusion**

This chapter has described my philosophy of research which drew on realism, abduction and analytical reflexivity and how my thinking developed. The qualitative methodological approach I took included the observation of involvement activities to understand practice and the context in which it took place. I conducted in-depth case studies, with an understanding of the importance of reflexivity in relation to my position as researcher in the creation of knowledge. Data were collected by observation and interview alongside collection and analysis of relevant documents. Appendix 7 provides additional reflection on the development of ideas presented in this chapter. The next chapter reports how I conducted the project.

## Chapter 4: Conduct of the project

### 4.1 Introduction

This chapter describes how I chose and recruited my case studies and participants, and provides information about participants, data collection and analysis. The chapter continues with reflection on ethical issues, including the withdrawal of the third case study, and provides a reflexive account of my position in the project.

### 4.2 Identifying the sample

Early in the project, following discussion with supervisors, a sample of three health research case studies was agreed as achievable within a doctoral research project. The sample was drawn from England because the jurisdiction for the NIHR and INVOLVE is England. Although one case study was based in England and funded by the NIHR some public involvement activity was conducted at a research site in Wales, therefore some data were collected in Wales.

#### 4.2.1 Inclusion and exclusion criteria

When completing the Integrated Research Application System (IRAS) form and applying for NHS favourable opinion I drafted a set of inclusion and exclusion criteria for case studies, see Table 4.

**Table 4: Inclusion and exclusion criteria for potential case studies**

<b>Inclusion criteria</b>	Research partners were involved in the research process. Sufficient public involvement was taking place to warrant inclusion. Involvement activities were taking place while my project was conducted. Research partners agreed to participate. Participants were adults with the capacity to consent. The geographical locations of public involvement activities were accessible for data collection.
<b>Exclusion criteria</b>	Research studies which were recruiting children and young people. Research studies where research partners did not agree to take part. Research studies that were completed. Research studies where public involvement activities had already been the focus of publication. Research studies that were not yet funded.

Case studies where research was not yet funded were excluded because funding might not be secured and because of the long gap between submission of funding applications and successful research starting. The development of these criteria in response to the IRAS form prompted reflection on how research governance systems influenced the development of my project.

### 4.2.2 Choosing and negotiating case studies

Two criteria were developed to choose case studies. The first was an initial assessment of whether sufficient public involvement was taking place to warrant inclusion. Assessment considered the three forms of public involvement described at that time (2011) by INVOLVE - consultation, collaboration and user-control (Hanley *et al.* 2003). I did not to seek a user-controlled case study because I wanted to understand how researchers and research partners worked together in health settings where research was led by academics or health professionals. My rationale was that many involvement opportunities in the West of England arise in such settings. While the number of involvement opportunities in research is difficult to determine (Breaking Boundaries Review Team 2015) 700 research partners had reviewed NIHR funding applications in 2013/14. This indicates the large number of research studies being considered in the NIHR, all of which require involvement. In contrast, Faulkner (2010) reports that in a mapping exercise INVOLVE had identified 45 service-user led studies.

The second criterion I developed was 'approach' to public involvement. This term combined the aim of involvement and whether or not there was a history of involvement in the research team. I identified three possible involvement aims, pragmatic (for example in response to research funder requirements), to improve research quality or to empower those involved. I wanted a varied sample based on these categories, see Table 5. A third, pragmatic, criterion was geographical accessibility for data collection.

**Table 5: Approach to involvement**

<b>Aim</b>	<b>Pragmatic</b>	<b>Improve research quality</b>	<b>Empowerment</b>
<b>Involvement history</b>	1	2	3
<b>No involvement history</b>	4	5	6

Colleagues advised me that it might be difficult to get support from researchers because of the need for extended access to research and involvement activities, and that support from senior researchers would be needed to make the project viable. Desire for a varied group of case studies was therefore accompanied by anxiety about recruitment. I was reassured that Silverman (2006) endorses a pragmatic choice of cases based on access.

Potential case studies were identified with my director of studies based on prior knowledge and through networks of contacts. I read publicly available information about possible case studies, researcher profiles, and publication lists for background and reference to involvement. In initial emails I described my project and provided information about myself and my experience of involvement, and attached a project summary and a CV, see Appendices 8 and 9.



Positive responses were followed up and more information about involvement was sought. Following these contacts, an initial assessment of the extent of, and approach to, involvement was made with my director of studies based on the information collected in this process.

Two of the cases chosen were assessed as aiming to improve research quality with some preceding experience of involvement, so both were located in cell 2 of Table 5. The third case study had no history of involvement, and assessment of aims combined cells 4 and 5; however this was the case study that was withdrawn, see section 4.7.2 for more information.

During the process of negotiating access I provided copies of the protocol, participant information sheets, consent forms, permission letters and my letter of access (see Appendices 10-19). Discussions with senior researchers identified all potential participants and agreed how they would be approached. The two case studies presented in the thesis were focused on research in rheumatology and domestic violence (DV).

The choice of the rheumatology case study was based on a strong history of public involvement in both service delivery and research, including publication on involvement. Two senior researchers were known to me and my director of studies and they supported the project. The first potential research study considered in rheumatology was delayed, but negotiations with the chief investigator of a second study went well and the case study was agreed. The study at the centre of this case aimed to develop an outcome measure for drug treatments for rheumatology based on patients' outcome priorities.

The DV case study was identified by a senior university academic who I had approached about another potential case which proved unsuitable; she identified two other possibilities in her department and emailed colleagues on my behalf. This support resulted in the DV case study; it was focused on involvement in a clinical trial of a psychological intervention for women affected by DV.

I had envisaged initial contacts with researchers as exploratory, with time to review the choice of case studies. However, positive responses felt like a provisional acceptance of my proposal. This dynamic was reinforced by power relations; I was negotiating with senior researchers as a doctoral student, and support generated feelings of relief, gratitude and commitment. In one case the process took on its own momentum when a senior researcher shared information about my project with colleagues; while I was delighted to recruit the case study the process did not unfold as anticipated.

Negotiating permission to conduct my project provided a reality check on my research design. In particular, plans for potential observations, including shadowing researchers, proved

impractical, as did systematically conducting follow up interviews. This became clear in early discussions about a rheumatology case study despite senior researchers being supportive.

In the DV case study, in addition to attending a local research team meeting, I went to a national meeting of researchers working on a group of related studies, because permission for my project was also needed from this group. In negotiations to conduct the DV case study it was agreed that I would not collect data from DV agency staff because the trial was already making significant demands on their time, from participants in the trial, or from agency staff delivering the trial intervention.

The process of gaining access to conduct my case studies had some features of conducting insider research in organisations (Costley, Elliott and Gibbs 2010), and accessing communities of practice (Wenger 1998). Although I was not a member of the research teams I investigated, nor employed by the same organisation, I was an involvement insider with its own, albeit informal, community of practice. In my project formal access was not agreed until the end of the process, in research governance approval from a NHS trust and local university. However, access was dependent on support from senior researchers and despite the development of criteria and assessment processes, the choice of cases was pragmatic.

### **4.3 NHS Ethical Approval and Research Governance**

The rheumatology case study was based in a hospital so it was clear that NHS Ethical Approval would be needed. Attendance at a Research Ethics Committee (REC) was followed by two rounds of questions and requests for further information. This lengthy and demanding process identified the tension between the requirement to specify the design and research processes in detail in advance and my project design. It took 3.5 months to secure favourable opinion to proceed.

The protocol identified three potential groups of participants (see Appendix 10) but I only recruited from one group. The other groups were conceived to support broader data collection but these plans proved impractical. Collection of data by photo elicitation was also in the protocol, but with support in supervision I decided I had insufficient capacity to manage additional data collection and analysis.

The REC required that I send out interview transcripts to participants for 'validation' and asked for structured interview questions. The committee also proposed that named support groups and a 24 hour support line (Samaritans) should be added to my participant information sheet. In response I added the Samaritans to a 'Sources of Support' sheet (Appendix 20) which had been submitted as a resource for any research partner participants who got distressed, and

argued that it was not appropriate to put this information in the participant information sheet; fortunately this was accepted. These requirements addressed some ethical risks related to the project, specifically potential distress and misrepresentation, but ignored other potential risks in qualitative research, including exploitation, identification of participants, inconvenience and opportunity cost (Richards and Schwartz 2002).

The REC also asked me to identify the case studies; this request was problematic because my understanding of ethical conduct included not approaching researchers formally about my project before I had REC approval because the lead researchers would be project participants. However, the process of identifying study sites (required in the IRAS process) and recruitment of participants were inseparable in my project, although these steps were logically discrete. This problem was resolved by providing information about a number of potential case studies to the REC. A substantial amendment was submitted in December 2011 to extend the period over which data could be collected, and for the use of a background information form (Appendix 21) to record demographic information about study participants. The amendment was approved in January 2012.

Research governance approval was subsequently sought from a local acute NHS trust and university to conduct the project, this process included applying for a Research Passport. All permissions were in place by January 2012. In addition my NHS ethics application was considered by the Faculty Research Ethics Committee in Health & Life Sciences at UWE and approved in February 2012.

Some authors question the expertise of ethics committees to judge social research and qualitative studies because the criteria they apply may work less well for such studies, and they are primarily concerned with clinical research (Miller 2012; Green and Thorogood 2014). The focus of regulation on anticipatory and pre-study review, with a tendency to foster a tick box mentality disconnected from the conduct of the project, has also been questioned for qualitative research (Dixon-Woods *et al.* 2007; Miller 2012). Requirements to pre-specify elements of research design were problematic because the protocol expressed my aspirations, some of which had to be modified as the project developed.

#### **4.4 Recruitment and consent**

As described in section 4.2, researchers involved in initial negotiations had had information about the project, including information sheets and consent forms among other documents. There were two versions of the participant information sheet, one for research partners and

one for researchers and research managers; the content was the same but wording differed (Appendices 9 and 10).

In both case studies I attended meetings to introduce myself and my project, to answer questions and discuss practical issues including recruitment of research partners. These meetings took place after I had received provisional support from lead researchers and combined a process of checking whether researchers were willing for my project to go ahead at all, and the process of providing information and answering questions prior to recruitment.

In the rheumatology case study consent was sought from potential participants individually once I had formal permission to proceed. In the DV case study I was invited attend a trial management meeting as an observer and needed to seek consent at the start of the meeting. It was my first observation and I wanted to be in the background, but the consent process delayed the start of the meeting with me at centre stage. This was uncomfortable although the researchers were friendly and supportive. All participants were experienced researchers familiar with the process of seeking consent, several supervised PhD students, and they had already received information about my project and effectively agreed to take part. I accelerated recruitment by not going through the information sheet in detail, but this felt risky because I did not know whether researchers would be critical or relieved. A few researcher participants did not have the opportunity to meet me because they were not based locally and participated in research meetings by teleconference, consent was sought from them electronically.

The recruitment of research partners was a source of concern; although researchers had provided them with information about my project and sounded them out about taking part at an early stage, until they agreed I was uncertain whether the case studies could go ahead. Fortunately all research partners agreed to take part when they were approached. The process of recruiting these participants followed the formal process, reflecting my own concerns to make sure research partners understood what I was doing and what was being asked of them, and researchers concern to protect them.

I emphasised that participation did not mean writing a 'blank cheque' regarding access to participants or research activities. Information sheets and recruitment discussions highlighted that access would be negotiated and renegotiated over the data collection period. Every effort was made to identify potential participants and approach them in advance but there were occasions in the DV case study when researchers or other staff attended research meetings without my prior knowledge. Adaptations to the consent process reflected the difficulty of

implementing the informed consent process required by the REC in a project including ongoing observations.

It was made clear verbally and in writing that all participants could withdraw from the project at any time and that this would not affect any research or involvement activities. The consent form offered an option to allow individual data already collected to be used for my project or for all individual data to be withdrawn, see Appendix 13. If a participant decided to withdraw they had the opportunity to review the decision they made about their data at the time they gave consent. However, the withdrawal of consent of a senior researcher in the third case study resulted in withdrawal of the whole case study from the thesis; additional reflection on this process is presented in section 4.7.2.

Informed consent is based on principles of voluntary and informed participation in medical research (Homan 1991), and is based on individual choice. However, Green and Thorogood (2014) point out that in some designs people are recruited as collectives rather than as individuals and this was applicable to my project, these issues are considered further in section 4.7.3. Hammersley and Traianou (2012) point out that there are also questions about what is consented to when data collection draws on a range of qualitative methods. In my project data collection described in the information sheet was more extensive than what was actually collected as a result of negotiating access, but still the implications of consent for observations was not unambiguous (see section 4.7.4).

#### **4.4.1 Participant numbers and demographic characteristics**

Table 6 shows the numbers of participants recruited by group (research partner, researcher, and agency staff) and case study. The DV case study was larger than the rheumatology case study but the numbers of research partner and research participants were well balanced in both.

**Table 6: Participants by group and case study**

<b>Case study</b>	<b>Research partners</b>	<b>Researchers</b>	<b>Agency staff</b>	<b>TOTAL</b>
<b>Rheumatology</b>	6	5	0	<b>11</b>
<b>Domestic violence</b>	12	15	8	<b>35</b>
<b>TOTAL</b>	<b>18</b>	<b>20</b>	<b>8</b>	<b>46</b>

The demographic characteristics of participants are presented in Appendix 22. Most participants were women (43). Two male researchers were the most senior participants in

both case studies. Most participants were white; fifteen were between 25-45 years and fourteen were between 46-64 years. None of the research partners were in full time work; they were more diverse in the DV case study, which included both participants under 25 years, all six participants with O level qualifications or less, and the three non-white research partner participants. The background information form used to collect this data (Appendix 21) was not returned by 13 participants who were only observed.

## 4.5 Data collection

Data were collected for the following periods between January 2012 and April 2013:

- Rheumatology case study 15 months
- DV case study 13 months.

A large amount of interview and documentary information was collected, but collection of observational data was more limited than I hoped. The volume of data collected differed, with most data collected from the DV case study. Table 7 summarises data collected by case study.

**Table 7: Data collected by case study**

Case study	Observations Number (hours)	Interviews Number	Documents Type (Number)
Rheumatology	2 (3 hours)	12	17 (22)
Domestic violence	16 (48 hours)	14	21 (51)
<b>Total</b>	18 (51 hours)	26	38 (73)

### 4.5.1 Observations

My plans for observations were modified and it proved impractical to observe researchers other than in scheduled meetings. Although I was able to conduct ongoing observations in the DV case study, there were few opportunities to observe involvement in the rheumatology case study. Delays in acquiring permission to start the project meant that an opportunity to observe a research team meeting in the rheumatology case was missed, and there was only one other meeting which included research partners in the following 15 months. Most research activities were conducted by two researchers. However, I was able to conduct two 'informal' observations at the invitation of researchers; nonetheless, this case study was more reliant on interview data than I anticipated. In contrast, there were many opportunities for observation in the DV case study.

In both case studies I was invited to attend a training day for research partners, and I also conducted three other 'informal' observations. These observations are described as 'informal'

because, although I was invited to attend, it was not possible to seek prior written informed consent from everyone taking part. At three of these observations I was introduced to everyone present and it was clear that I was conducting a research project which had prompted the invitation. I attended a departmental Open Day in the rheumatology case study which was open to the public and a meeting for DV researchers where I introduced myself but gave no specific information about my project. I made field notes following these observations and they provided background information. Reflection on the ethical issues relating to these ‘informal’ observations is reported in section 4.7.4 below.

Where possible I audio-recorded meetings; field notes included a description of the room, who sat where, reflections on relationships, emotions, and physical aspects of interaction. Brief written notes were made during meetings and fleshed out afterwards, as soon as possible. Some audio recordings of meetings were transcribed verbatim (all meetings including research partners) and others were partly transcribed, where discussions with less relevance for involvement were summarised. All transcripts and field notes were imported into Nvivo 9 (QSR International 2010) and analysed as described in section 3.2.3, and below in section 4.6. Tables 8 and 9 describe the observations conducted.

**Table 8: Observations in the rheumatology case study**

	<b>Observations Number (hours)</b>	<b>‘Informal’ observations Number (hours)</b>	<b>Description</b>
<b>Rheumatology case study</b>	1 (2)		Research team meeting including research partner
	1 (1)		Clinic visit with lead researcher.
		1 (6)	Training day for research partners. I jointly ran a session on this training day.
		1 (4)	Departmental open day
<b>Total</b>	<b>2 (3)</b>	<b>1 (10)</b>	<b>3 (13)</b>

**Table 9: Observations in the domestic violence case study**

	<b>Observation Number (hours)</b>	<b>‘Informal’ observation Number (hours)</b>	<b>Description</b>
<b>DV case study</b>	4 (12)		Involvement meetings
	12 (36)		Research meetings (researchers only)
		1 (5)	Training day for research partners
		1 (2)	Meeting to discuss involvement strategy
		1 (5)	Meeting of DV researchers
<b>Total</b>	<b>16 (48)</b>	<b>3 (12)</b>	<b>19 (60)</b>

In the DV case study data were only collected from some participants by observation. Two research partners from two involvement groups (n=4) were interviewed, the remainder (n=8) were observed only. Data were collected from five researcher participants in this case study only by observation of research meetings.

### ***Becoming a participant observer***

My philosophy of research informed my stance in observations. A realist epistemology argues that knowledge of the social world is necessarily perspectival and 'situated' (Carter and New 2004), and researchers are part of the social world studied (Hammersley 2004; Green and Thorogood 2014). In section 1.2.1 I described how ongoing policy commitments and research funder requirements drive involvement whatever the values and beliefs of researchers, placing research on this topic in a political context. In collecting data I became part of the worlds I studied, with a focus on the conduct of a politically endorsed activity, therefore, whether or not I took part in activities my presence would have an impact on the behaviour of participants. While such impacts were not easily identifiable, they were likely to include increased awareness of public involvement when I was present.

When I started to collect data I positioned myself as 'observer-as-participant' (Green and Thorogood 2009), I sat at tables with researchers, overtly took some notes, and did not contribute to discussions. However, my stance included close association with the setting and participation in activities (Brewer 2000; Burgess 1982), where participation still emphasised data collection so that the group were aware of observations (Kawulich 2005). Participation was understood as improving observation and generating more complete understanding. DeWalt and DeWalt (2002) affirm that participant observation helps to develop a holistic understanding and increase validity by providing a better understanding of both context and phenomena being studied, particularly when combined with other data collection methods.

In the rheumatology case I only observed one meeting, but in the DV case study I conducted regular observations for over a year. In the DV case study my ability to provide relevant information about involvement was perceived by some participants as a benefit of contributing to the project. Over time I developed relationships and more of an insider view, becoming more aligned with research participants (McKinley Brayboy and Deyhle 2000). This included moving from an exclusively observational role to becoming a more active participant observer.

In research, insider and outsider status refers to the degree to which a researcher is located either within or outside the group being researched (Gair 2012); for some an outsider stance is seen as protection against over-identification, whereas others consider a researcher with



insider knowledge desirable and more legitimate. However, the insider/outsider dichotomy is recognised as simplistic (De Cruz and Jones 2004; Breen 2007), and a more complex shifting or fluid divide between insider/outsider status is accepted by many (Boulton 2000; Haviland *et al.* 2005; Ochieng 2010).

My position in this project reflected such complex positioning, I was an insider in the involvement in research field, I shared the identity of research partner with some of my participants, but I was an outsider in relation to the research areas of rheumatology and domestic violence, and while I had some research experience I had no experience of conducting health research in these specialist fields. My status as a doctoral student was junior in relation to many of the researcher participants, and while I shared research partner experience with research partner participants I was clearly also an involvement professional (Thompson *et al.* 2012) and a doctoral student. My expertise on involvement gave me additional status and my focus on the gap between theory and practice in involvement demonstrated a prior understanding that practice did not necessarily live up to aspirations.

My methodological position located me within the social world I researched, inevitably affecting it whether or not I participated. I chose to engage in close association with one case study setting, and as a participant observer gained a deeper understanding of involvement activities and contextual contingencies. While this choice increased my impact on involvement activities and on the data generated, the increased understanding gained outweighed this researcher effect.

#### **4.5.2 Interviews**

My approach to interviews and the questions asked are described in section 3.4.2. Interviews took place in quiet locations at a date, place and time determined by participants at their convenience. Interviews were preceded by an introduction, where the purpose and duration of the interview was explained and agreed. Reminders were given about being able to stop at any time or have a break, and that the recording would be typed up. Participants were offered the opportunity to review the transcripts, check them for accuracy and add further reflections or clarification, but few chose to do so. Some participants were sent a copy but returned no comments; two sent a response, only one made a correction (of spelling).

Most interviews took between 45 minutes and an hour, some were longer. Interviews with researchers took place at their workplace, apart from one which was conducted at an alternative venue for privacy. Research partner interviews took place in a variety of venues as

follows: in participants' homes (3), my home (1), in a DV agency or community centre (3), in a NHS or university environment (3).

All interviews but one were audio recorded and transcribed verbatim. Some audio recordings were not transcribed by me. Written notes were taken and typed up in the interview that was not recorded. Transcripts of interviews were imported into Nvivo 9 (QSR International 2010) and analysed as described in sections 3.2.3, and 4.6 below.

Twenty-six interviews were conducted with research partners and researchers, follow up questions were asked during observations and in other informal contacts with participants. See Table 10 for interview numbers by case study and participant group.

**Table 10: Interviews conducted by case study and participant group**

<b>Case study</b>	<b>Research partner (total number of participants)</b>	<b>Researcher (total number of participants)</b>	<b>Total</b>
<b>Rheumatology</b>	6 (6)	6 (5)*	12
<b>DV</b>	4 (12)	10 (15)	14
<b>Total</b>	<b>10 (18)</b>	<b>16 (20)</b>	<b>26</b>

\* Two interviews were conducted with one participant.

A support and safety policy for data collection was agreed which included interviewing at participants' homes, see Appendix 23. This entailed providing information about my location, interview times and notifying my director of studies when I had completed an interview

### **4.5.3 Documents**

Research documents collected included the funding bid, ethics form, protocol, and meeting notes. Other relevant documents for involvement were identified in discussion with participants. Documents were mainly collected electronically. The documents collected and analysed are listed in Tables 11 and 12. The amount of relevant information in documents varied substantially. My approach to documentary analysis is described in section 4.6.1.

**Table 11: Documents collected from the rheumatology case study**

Reference	Number	Description
D1	1	Funding bid draft 22/3/10.
D2	1	IRAS form dated 27/7/11.
D3	1	Confidentiality agreement for research partners (not dated but had been in existence for several years).
D4	1	Study protocol dated 16/8/11.
D5	1	Invitation letter for study participants dated 19/8/11.
D6-D8	3	Patient information sheets dated 31/8/11.
D9-D10	2	Schedule for consultation meetings 1 and 2 and voting slips dated 24/8/11.
D11	1	Letter to invite RP2 to contribute as a research partner to the study dated 26/10/11.
D12	1	Minutes of research team meeting 21/12/11.
D13	1	Form to record impact of research partner contributions to research studies dated 31/1/12.
D14-D15	2	Phase III draft questionnaire dated 3/2/12 and copy with research partner comments dated 15/2/12.
D16	1	Group of emails between researcher and involvement co-ordinator forwarded to me on 17/2/12. These emails referred directly to involvement systems in the department.
D17-D18	2	Flier and poster for departmental open day 29/6/12.
D19	1	Abstract of a presentation on research study findings at conference held in November 2012.
D20	1	Research team meeting agenda 30/1/13.
D21	1	Draft article reporting study findings for discussion at team meeting on 30/1/13.
D22	1	Participant summary (of research findings circulated to all study participants at the end of the research study) dated 8/3/13
<b>Total</b>	<b>17 different document types (22 in all)</b>	

**Table 12: Documents collected from domestic violence case study**

Reference	Number	Description
D23	1	IRAS form dated October 2008.
D24	1	Terms of reference for involvement group. Not dated but produced when the study was being designed.
D25	1	Report on prior related research study dated February 2011.
D26	1	PPI section from NRES application date unknown.
D27	1	PPI section from protocol date unknown.
D28	1	PPI meeting agenda held at agency 2 16/3/12.
D29	1	Programme for research partner training day 14/3/12
D30	1	Emails giving feedback on training forwarded to me 19/3/12.
D31	1	PPI meeting agenda held at agency 2 19/6/12.
D32-D34	3	Papers for PPI meeting at agency 2 19/6/12 –overview of progress on the research study; leaflet for another DV study; draft application form for a third (new) DV study.
D35	1	Agenda PPI meeting held at agency 1 29/11/12.
D36	1	Progress report on the research study for PPI meeting at agency 1 29/11/12.
D37	1	Notes of PPI meeting held at agency 1 on 29/11/12
D38-D52	15	Agendas for TMG meetings between March 2012 and April 2013.
D53-D67	15	Notes of TMG meetings March 2012-April 2013.
D68	1	Draft leaflet to replace terms of reference for involvement group dated 17/12/12.
D69	1	Paper titled 'Moving forward with Patient and Public Involvement (PPI)' dated 12/2/13.
D70	1	Covering letter sent to research partners with questionnaire
D71	1	Questionnaire about involvement group sent out to research partners sent out March 13.
D72	1	Summary of feedback from questionnaire sent out to research partners dated 16/8/13.
D73-D74	2	Newsletters Spring 2013 dated March 2013 and Summer 2013 dated June 2013.
<b>Total</b>	<b>21 different document types (52 in total)</b>	

## 4.6 Data analysis

Drawing on Alvesson and Sköldbberg (2009) I analysed data from three perspectives: empirical and more inductive, theoretical and more deductive, and with a focus on power as described in section 3.2.3. Most data were analysed using Nvivo 9 (QSR International 2010), but handwritten field notes and diagrams were coded and analysed manually.

Data were analysed in two sets, the first including all interview and observational data across all three cases<sup>1</sup>, the second comprising documents. Thematic analysis of the interview and

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<sup>1</sup> Withdrawal of the third case study happened after all analysis had been completed.

observational data was conducted based on Braun and Clarke (2006). I familiarised myself with all data; this included transcribing some data items, and checking all transcripts against audio recordings for accuracy. For the first phase of analysis I read and re-read data and generated codes systematically across all data items, and subsequently grouped codes into themes. This process generated 326 codes which were collated into potential themes as analysis progressed; initially 18 themes were identified, each with sub-themes. This analysis was conducted intensively alongside data collection during 2012. Systematic review and refinement of themes and codes started in the autumn of 2012 which reduced the number of themes to 11. Up to this point my data analysis followed Braun and Clarke's (2006) first four phases of thematic analysis. Appendix 24 provides an annotated data extract showing coding, and part of the coding structure and the themes in development to show this process of analysis.

The second phase of analysis started in early 2013 when the themes and codes were reviewed in relation to key issues and themes emerging from the literature review. Attending to issues of importance in the literature sharpened my focus from the wide range of issues of interest within the data and experiences of involvement per se, to what these data and experiences said about the project's questions, and in particular on how they related to the gap between involvement practice and theories of involvement. Some themes were common to both analytical structures, but consideration of themes generated from the literature led to reorganisation and refinement of the analytical structure developed in the first phase of analysis. All data were reviewed again in relation to the revised structure of themes and codes. Review of the analytical structure and data from a more theory driven perspective resulted in the reduction in number of themes to five with 37 sub codes.

There were few data directly related to the purpose or rationale for involvement, an important theme identified in the literature, but relevant data were collected about involvement tasks and roles. Distinguishing outcomes of involvement on research processes from impacts on research partners and researchers was drawn from other studies (Staley 2009; Brett *et al.* 2010). Several themes identified in the first phase of analysis were streamlined to form the 'processes, mechanisms and resources' theme in the final structure. Some of the sub-themes were important from a theoretical perspective, but contained a small amount of data (in particular legitimacy and representation). Although power issues were identified as a significant issue in the literature, the more inductive analysis had identified few codes directly related to this topic. In the final phase of analysis all data were reviewed with a focus on power which became the sixth theme.

Further work took place to refine the themes and sub-themes during the latter part of 2013.

The final themes and main sub-themes identified were:

- Involvement tasks and roles
- Impact of involvement
  - On research processes
  - On research partners and researchers
- Processes, mechanisms and resources
  - Learning and development
  - Payment
- Context of involvement
  - Leadership
  - History of involvement
- Who was involved
  - Recruitment
  - Legitimacy and representation
- Power

The themes and codes that were generated during analysis identified patterns in the data across cases, but thematic data were presented by case. At the same time as undertaking this project I also contributed to another research study on public involvement in research which conducted eight case studies (Evans *et al.* 2014). In this project data were presented by theme, and it became clear that this approach made understanding each case as a coherent whole difficult. This experience influenced my choice to present the data by case. My interest in presenting data in context is supported by Richards and Schwartz (2002), who acknowledge that contextual data are often essential in qualitative studies. In early 2014 I worked intensively on drafting the case study chapters, which included selecting extracts to illustrate themes within each case and relating the analysis back to my research questions.

#### **4.6.1 Documentary analysis**

Documents were analysed as a second data set, following thematic analysis of interview and observational data in late 2013. They were analysed from different perspectives, which included content analysis based on the themes identified in observational and interview data. In addition, documents were considered as potentially active agents.

Prior (2008) proposes that documents can be seen as actors in their own right, and that emphasis on content excludes interest in how documents are used in social interaction. He

suggests a counterbalancing focus on how content came into being, and on document use and function. Prior (2008) provides a matrix of approaches to the study of documents and describes how the focus of interest changes for each cell, see Table 13. I used this matrix to structure my analysis of documents, where cell one analysis was based on the themes developed in the first data set.

**Table 13: Matrix for analysis of documents**

<b>Focus of research approach</b>	<b>Document as resource</b>	<b>Document as topic</b>
<b>Content</b>	1. Approaches that focus mainly on what is 'in' the document.	2. 'Archaeological' approaches that focus on how document content comes into being.
<b>Use and function</b>	3. Approaches that focus on how documents are used as a resource by human actors for purposeful ends.	4. Approaches that focus on how documents function in, and impact on, schemes of social interaction and social organisation.

Adapted from Prior (2008 p. 825)

I also drew on Gibson and Brown (2009) who suggest keeping individual record sheets for all documents to keep track of all questions posed and emerging issues. They propose records should include: date, author, purpose, audience, relation to other documents, ownership and alteration. I created a template for analysing documents including Prior's (2008) cells and questions from Gibson and Brown (2009) which was completed for each document.

Findings from documentary analysis are reported within the structure developed for set one as no additional themes of importance were identified in this analysis.

#### **4.7 Ethical dilemmas**

A number of ethical issues that arose in the conduct of this project are described in this section; the most significant of them resulted in the withdrawal of the third case study from the thesis which is described in section 4.7.2 below.

Goodwin *et al.* (2003) describe ethics as an ever present concern, pervading every aspect of the research process, including the dissemination of results. Shaw (2003) agrees that ethical issues emerge at all stages of research, and argues for ongoing reflection on ethical issues throughout research without undue emphasis on initial ethical approval processes.

Hammersley and Traianou (2012) challenge conceptions of research ethics that treat it as the following of procedures designed to protect the rights and interests of those from whom data are collected, and instead suggest it entails weighing a variety of considerations against each

other, where ethical judgement is primarily about which compromises are and are not legitimate in context. Section 4.3 has described the process of gaining formal approval for the project; this section describes ethical issues that emerged as the project progressed.

#### **4.7.1 Confidentiality**

The design of the project raised some important issues in relation to confidentiality. I decided to write up my findings by case to promote understanding of involvement in context, see section 4.6. While this had benefits for the project, it made protection of confidentiality more difficult, particularly as participants knew each other. The significant challenge of maintaining confidentiality in qualitative research seeking to present holistic accounts, including presentation of raw interview and observation data is identified by a number of authors (Forbat and Henderson 2003; Goodwin *et al.* 2003; Ellis 2007). In addition, the risk of breaching confidentiality increases when research participants know each other (Damianakis and Woodford 2012).

I used many tactics identified by Damianakis and Woodford (2012) to reduce risks to confidentiality, including identifying participants' only by code, giving people the right to refuse to answer questions or withdraw at any time, and removing identifying information. However, Richards and Schwartz (2002) point out that even anonymised qualitative data may provide enough information for participants to identify themselves or others, and that it is not always easy to predict what data will lead to identification.

Consideration of draft findings made it clear that participants could potentially identify each other. This emphasised the need to be aware of sensitivities between participants. Consideration of this issue is described as a key element of researcher reflexivity by Damianakis and Woodford (2012). I spent significant time considering these issues and discussed them in supervision; however judgements about such issues could be fallible.

While other readers were less likely to be able to identify participants, it was difficult to disguise the case studies and include contextual information, for example, changing the health topics would have removed meaning. However, providing this information meant that a determined reader might identify the institution, the specific research study, and some researcher participants. These issues were considered in supervision in order to develop an approach which balanced accurate reporting and concerns about confidentiality. It became clear that given the research design and approach taken to reporting findings, confidentiality could not be protected to the level possible in other research designs. The potential to reveal researcher identities adds another layer to the complexity of maintaining confidentiality and privacy in qualitative research. Morse (2007) argues that confidentiality should not be



promised in consents in qualitative research in health care settings, and perhaps such changes should be extended to other areas.

In response to these issues I sent a draft case study to some participants so that they could review the analysis prior to presentation in the thesis. Ellis (2007) suggests this is a helpful additional means of gauging participants' approval of their representation in findings. The draft case studies were circulated to key participants when analysis was completed, and the whole thesis had been drafted. This timing was chosen to ensure that the review process was based on the case study chapters as they would appear in the thesis.

Some participants were chosen because they were more exposed in the analysis than others. The decision about which participants should review the chapters was decided on a case by case basis. In the rheumatology case study all participants were sent the draft chapter. In the DV case study a group of key researcher participants were sent the draft chapter because the whole participant group was large and many participants, including research partners, were not identifiable.

This process potentially compromised the reporting of issues that were perceived as sensitive, raising the question of whether generating knowledge or upholding ethical standards is more important (Guillemin and Gillam 2004; Kaiser 2009). However, although some sensitive issues were identified in the draft chapters, and some amendments were made after discussion with supervisors prior to circulation, I chose not to restrict reporting of significant analytical issues.

Another implication of the protection of confidentiality was that I could not reference publications on involvement written by participants when comparing the case studies and discussing findings. While I made efforts to protect confidentiality and check on the acceptability of my representation of participants, if I conducted a similar project again I would add information about potential issues relating to confidentiality to the consent form as suggested by Damianakis and Woodford (2012). Most of these considerations were relevant for all case studies. The next section describes the events that led to the withdrawal of the third case study which reflect many of the issues identified in this section.

#### **4.7.2 Withdrawal of the third case study**

Three case studies were conducted but only two are reported in the thesis. One participant in the third case study withdrew consent when they reviewed the draft chapter presenting analysis of data. This was a senior researcher and key participant, and with the support of my supervision team, it was decided that the most appropriate response was to withdraw the case study from the thesis.

When discussing the draft chapter of this case study in supervision some sensitive issues were identified and several amendments were made before it was sent out. One participant was judged to be particularly exposed in the analysis, so the draft chapter was only sent to this participant. While some issues had been identified, the significant problems that emerged were unforeseen; however, Goodwin *et al.* (2003) report that contextually specific ethical issues are often difficult to anticipate.

Review of the chapter by the participant identified a number of issues and consent was withdrawn. Concerns focused on potential for identification outside the participant group, and sensitivity of findings, not the accuracy of findings. My first response was to apologise. The participant provided an annotated chapter. I addressed all issues and the revisions were reviewed by my director of studies. Unfortunately this process compromised the analysis to some extent. Neither did it result in agreement or renewed consent when it was reviewed for a second time.

In considering relational ethics Ellis (2007) suggests that researchers might prepare a first uncensored draft of findings, and then consider the ethics of 'what to tell'. Damianakis and Woodford (2012) emphasise a dual mandate in qualitative research, to both generate knowledge and uphold ethical standards and principles. They argue that both are equally important, but if an ethical choice must be made preventing harm to participants should take precedence. The choice to withdraw the case study was based on ethical values rather than a specific code of practice, alongside the considerations described below. Goodwin *et al.* (2003) also identify that codes of practice do not resolve all ethical dilemmas and that choices have to be made on the basis of principles and values.

A number of issues were considered when making this decision:

1. The case study was small in comparison to the other two cases.
2. The data from the participant who withdrew consent were central to the findings.
3. Without data from the participant who withdrew consent the remaining case study would be weak and compromise the reporting of findings further.
4. While the consent form allowed individual data to be withdrawn, discussion in the supervision team identified problems with this course of action.
  - The meaning of data in the case study were interdependent and withdrawal of key data undermined coherence of findings.
  - Other researcher participants were aware that the senior researcher who withdrew consent had contributed to the project. Therefore, if a revised chapter, based on data from four rather than five participants, had been

circulated it would have been obvious that data had been withdrawn.

Circulating a revised case study would therefore have exposed the participant who had withdrawn consent to colleagues.

- Other participants might have wished to reconsider their own contribution in the light of the withdrawal of a colleague. However, this could not be discussed with them.
- The potential strategy to present data by theme, rather than by case, would have undermined my aim to present situated findings. It was not clear that this strategy would resolve the identified problems, and doing this required substantial revisions at a very late stage.

My response to this situation was also based on consideration of ongoing professional relationships. My director of studies was the lead for involvement in a regional initiative and I had been appointed as a research fellow for involvement at NIHR CLAHRC West. Therefore, actions in relation to the case study and doctoral project had to be considered in the light of ongoing relationships with researchers.

The case study was withdrawn in April 2014. This was a major blow, and posed further problems in that analysis, findings, discussion and theoretical development had drawn on all three case studies, and I could no longer present all the data which underpinned my work. Although withdrawal of the case study was a significant problem there were some mitigating factors. It was a small case study based on plans to develop an involvement initiative, but during data collection little progress was made and no involvement had taken place. However, the context of the withdrawn case study was more challenging for involvement than the other cases, and analysis of contextual factors in this case was significant in the development of my thinking. I have provided some anonymised reflection in section 7.5.3, based on observations, rather than interview data, to provide some access to this process.

#### **4.7.3 Choice to participate**

The wording of the information sheets and consent form made it clear that potential participants did not have to take part in my project, with the assumption of individual and autonomous choice (Green and Thorogood 2014). However, researchers and some research partners were recruited as members of a research team or involvement group where researchers were gate-keepers. Gate-keepers are understood to be potentially influential on the participation of other group members (Green and Thorogood 2014) with the implication that it may be difficult for other members to refuse when those in more powerful positions act as gate-keepers (Miller and Bell 2012). However, while the notion of voluntary consent refers

to the extent to which a person might feel pressurised to give or withhold consent, Hammersley and Traianou (2012) point out that people never operate in a social vacuum, separate from organisational and other contextual influences, including power structures, so decisions about participation in research are likely to be shaped by such factors. While such factors are common, the researcher is required to make a judgement about the particular situation.

On reflection, therefore, the statement on the consent form did not necessarily reflect participant experiences. The research design, in particular observation of research team meetings, compounded this problem, because one researcher's decision not to participate raised questions about the viability of the project, and at a minimum would have raised difficult questions about how data collection could be managed. Where initial discussions about my project were held in research team meetings, group dynamics and power relations would have influenced discussions, and if it was clear that a researcher was an important potential contributor because they supported public involvement activities, choice to participate might have felt compromised. In one early research meeting I left the room to allow discussion of the project without me, but power relations and team dynamics could still have constrained choice. It was possible that similar dynamics might have affected research partners; while researchers sent them information about me and my project in advance, and checked out whether it was alright for me to go along to meet them to discuss the project, once I was in the room it was likely to be more difficult to refuse to participate.

Awareness of this issue was highlighted when one of my researcher participants shared concerns about taking part in the project before an interview despite having given prior consent. I was disturbed by this disclosure and managed the issue in a way that was acceptable to the participant on the basis of a candid and careful discussion. However, afterwards I reflected that not all participants might have been able or willing to be so open, and that it was somewhat naïve in a project of this design to rely on formal statements about voluntary consent. This was a sensitive issue which I discussed in supervision; unfortunately, it is also difficult to write about in more depth because of the need to maintain confidentiality.

Following this event I was more aware of this dilemma with all participants. I addressed this potential problem by emphasising that any specific request I made to collect data could be refused, and by being respectful of participants' choices about how much to share with me. However, such strategies tend to build trusting relationships, so are not unambiguous ways to support limits to participation or withdrawal.

#### **4.7.4 Conduct of observations**

There were some ethical tensions related to data collection; in research governance processes data collection was understood as a discrete process only conducted after a researcher had received informed consent from a participant, where there was a clear boundary around data collection activities. However, observations included making field notes of informal contacts and interactions as well as observing research and involvement meetings.

These differences generated ethical tension; while I had permission to conduct observations, once the project had started I was not always sure that participants remembered the implications of this data collection method. I wrote field notes following data collection activities which included informal discussions with participants. I negotiated my uncertainty about participants' understandings of observations by exercising judgement in the use of field notes for data analysis, based on my interpretation of the status of different interactions.

This first arose in an early discussion about my project with two researchers where the interpersonal dynamics were odd and I felt some ambivalence directed at me. I wrote field notes following this meeting, but then realised that I was not sure whether the participants had been aware that I would do this and that my notes were data, even though they had given informed consent for observations. The ambiguous nature of the contract between us was compounded because practical plans for the conduct of my project were being discussed. After discussion in supervision it was agreed it would be acceptable to use the data but not to quote the participants. Such dilemmas about the status of some conversations as data are not uncommon; Goodwin *et al.* (2003) reported this concern in a study of expertise in anaesthesia, and it has also been reported by others (Dewalt, Dewalt and Wayland 1998; Dingwall 1980).

I was also invited by researchers to attend some events because they were relevant for my project, but it was impractical to seek prior written informed consent from everyone attending. This included two training events for involvement and a meeting of researchers to discuss involvement strategy; these situations were potentially important sources of data for my project. After discussion in supervision I attended these events 'informally' and made field notes afterwards and the notes were used to provide background information. My presence at these events did not feel inappropriate or unethical to me; everyone at these events knew about my project and why I had been invited. Nonetheless, these situations highlight that the boundaries of data collection were more problematic given my research designs.

#### **4.7.5 Participant access to data**

Wherever possible I audio recorded meetings which I observed so I had an accurate record of discussions. Participants referred to this process from time to time and early on in the project

one passing reference made me aware that I might be asked for a transcript by a researcher participant to supplement her notes of a meeting. As a result I discussed this possibility in supervision. My feeling was that I should provide access to the data if it was requested and that would be problematic to deny access, particularly as the project offered the opportunity for respondent validation to increase credibility by checking transcripts and review of findings (Bryman 2008). However, my supervisors were not sure that research governance processes would endorse such data sharing and pointed out that one participant was seeking access to collective data, not personal data. Whilst this was an ethical dilemma we agreed that it was likely to be better for field relations to share data. My hunch about being asked for data was proved correct and I chose to share a transcript of a meeting with a researcher to supplement her written notes.

#### **4.8 Identity, disclosure and position**

The preceding sections of this chapter provide information and reflection on the conduct of the project. My reflexive strategies included participant checking of transcripts and review of case study drafts, and writing my research diary included ongoing consideration of the conduct of the project, including thinking about my own impact, and recording the development of my ideas. This section provides a brief account of how my position, identity and previous experience informed the conduct of the project, in addition see Appendix 25.

I chose to disclose my identity as a mental health service user and experienced research partner to all participants. Personal disclosure is central to the involvement role and was, therefore, a routine part of my work as a research partner and service user researcher. Self-disclosure is associated with the development of rapport in research relationships but in tension with the need for 'being professional' (Dickson-Swift *et al.* 2009); where motivation for self-disclosure includes a desire to demonstrate understanding of participants' situations, and to create a 'level playing field'. This contrasts with health professionals being warned against self-disclosure as creating boundary problems (Walker and Clarke 1999). My self-disclosure was intended to increase my credibility as someone with involvement experience as a research partner and researcher, and I hoped that it would help to 'level the playing field' to some extent because I was sharing information as well as seeking it. Such disclosure has been found to modify behavioural norms within research meetings, where norms often include maintaining emotional neutrality (Kleinman and Copp 1993) with little personal disclosure.

My role status in relation to participants was varied, from doctoral student collecting data from senior researcher participants, including medical consultants and professors, to peer relationships with some experienced research partner participants, to having higher status (as

researcher and professionalised research partner) with some less experienced research partner participants. My involvement experience also situated me as having relevant expertise in relation to the topic of my project. In addition, I held paid involvement roles before, during and after the project, which entailed ongoing working relationships with researchers and research partners from different universities and hospitals in the area, and membership of INVOLVE. This included working with two of my supervisors, including my director of studies. Role complexity has been associated with occupational stress (Kay 2000; Dollard 2003) and conflict in the conduct of research when researchers also had other professional roles was reported by Dickson-Swift *et al.* (2009).

In section 4.2.2 I describe how my prior relationships and network supported negotiations to conduct my project. I also had prior and ongoing collegiate relationships with some researchers and research partner participants that overlapped directly or indirectly with the conduct of the project. In the rheumatology case study prior relationships with participants included limited relationships with two senior researchers and relationships with some research partner participants: one I knew well, two others I had met on a number of occasions. However, in the DV case study I had no prior relationship with researchers or research partners, but since data collection I have worked with two of the researcher participants in my paid involvement role at NIHR CLAHRC West.

My position as a research partner may have positively influenced recruitment of research partners; however, section 4.7.3 outlines other factors that could have affected recruitment. In relation to data collection my experience gave me insider knowledge to draw on which helped me to understand and enquire about participants' experiences of involvement. Such experiences can shape the research relationship and affect the information that participants are willing to share (Berger 2015); however my experiential expertise was significantly different from research partner participants' experiential expertise. Having relevant experience has also been seen as influencing the way the researcher constructs the world, uses language, and chooses the lens for filtering information gathered and makes meaning (Kacen and Chaitin 2006), thus shaping findings and conclusions. This increases the need to monitor the tension between involvement and detachment to enhance the rigor of the research (Bradbury-Jones 2007; Pillow 2003), where reflexivity supports researchers to think about how who they are may both assist and hinder the co-construction of meanings (Lietz, Langer and Furman 2006). I used my research diary and memos to support this process in the project.

## 4.9 Conclusion

This chapter has described how case studies were chosen and negotiated, how participants were recruited, and how data were collected and analysed. A number of ethical dilemmas arising in the project are reported, including withdrawal of the third case study which raised a number of complex issues. This was a difficult process to negotiate with implications for reporting findings by case. While the methodology supported the production of situated knowledge it also posed challenges for the conduct of the research. Woven into this chapter is a reflexive account of the project including reflection on my identity, position and self-disclosure. Having described how I conducted the project in this chapter, the following two chapters report on the findings from case studies.

## 4.10 Presentation of data in case studies

In the case studies I have presented quotes in the text in the following ways:

*Participant descriptor: quote from interview transcript [with added explanatory or substituted words like this]*

*Date and participant descriptor: quotes from audio recorded observations and field notes shaded like this.*

*Document descriptor: quote from document with lines at the side like this.*



## **Chapter 5: Rheumatology case study**

### **5.1 Introduction**

This chapter presents analysis of data from the rheumatology case study. It took place in a setting where researchers were located in a research unit adjacent to a rheumatology department in a city centre hospital. Staff from the hospital and two universities worked together and the head of department and consultant nurse combined clinical and academic roles. Patient care was delivered on this site by a multi-disciplinary staff team. There was a long history of involvement in patient care, teaching and research and a large group of research partners were supported by a part-time paid co-ordinator.

The case study reports on involvement in a research study which was conducted between October 2011 and March 2013. The study was based on prior research which had developed a patient-generated core set of priority treatment outcomes for drug treatments in rheumatoid arthritis. The eight areas that had been identified and prioritised were: pain, joint damage, activities of daily living, mobility, life enjoyment, independence, fatigue and valued activities. Not all of these outcomes were being assessed when drug treatments were being decided for rheumatology patients and in order for the eight outcomes to be included in clinical trials, an appropriate outcome measure needed to be developed. The research study therefore aimed to identify and assess existing validated outcome measures in relation to the eight outcome areas, and to construct numerical rating scales with rheumatology patients where appropriate measures did not exist. Assessment and construction of new measures was followed by a proof of principle study to find out if they contributed additional information compared to existing validated measures and to understand their potential significance for patients and health professionals.

The research protocol set the scene for the study by saying that traditionally rheumatologists and other health professions had decided what outcomes should be measured and standardised in core sets, but that they did not cover all outcomes known to be important to patients. The protocol argued that the patient perspective was not captured by conventional tools, and that, despite support for the development of patient reported outcome measures (PROMS), currently used PROMS were not synonymous with the patient perspective.

The research study had three phases, in phase 1 consultation meetings were conducted with rheumatology patients. Phase 2 comprised focus groups with a different group of patients to further develop the measure. Phase 3 was a comparative study to see how the measure developed in phases 1 and 2 compared to existing measures.

Participants in this case study are referred to in the text and in quotes as shown in Table 14 below. It is important to note that there were only two research partners working in the research partner role on the research study at the centre of this case; they were RP1 and RP2. The other four research partner participants provided a variety of perspectives; three had contributed to the research study as participants in phase 1, all four had extensive experience of involvement in research in the department, RP3 was the current involvement co-ordinator, and RP4 chaired a patient advisory group.

**Table 14: Participant descriptors in the rheumatology case study**

	<b>Name</b>	<b>Code in text and quotes</b>
1.	Chief investigator	R1
2.	Research fellow	R2
3.	Head of department	R3
4.	Consultant nurse	R4
5.	Researcher	R5
6.	Research partner	RP1
7.	Research partner	RP2
8.	Involvement co-ordinator	RP3
9.	Research partner	RP4
10.	Research partner	RP5
11.	Research partner	RP6

The chief investigator and research fellow conducted all research activities. The research team included four other researchers and both research partners; it only met once in my data collection period. The only team member who did not participate in my project was the statistician.

All eleven participants were white, two were men (R3 and RP1), and two were under 45 years. Three of the six research partners were retired, four had a degree; day to day activities were limited a little for three, and a lot for three.

Data were collected from January 2012 to March 2013 which included the last two phases of the study to completion. See Appendix 22 and section 4.4.1 for more information about the characteristics of participants and data collection. I had existing relationships with both researchers and research partners in this case study, although I had not met RP1 or RP2 before.

## 5.2 Involvement tasks and roles

This section reports on involvement activities observed and described, alongside data on involvement roles.

### 5.2.1 Involvement in study design

There was a research partner involved when the chief investigator and colleagues devised the application to fund the research study who reviewed the lay summary and some sections of the application form to make sure they were accessible, but this research partner was not involved in the conduct of the study. The chief investigator explained that there was a long delay between the funding application and the start of the study and that, when contacted again, he no longer wanted to be involved.

This was a small research study (total budget under £30,000); the funding bid dated March 2010 (D1) included a brief section on user involvement. The information provided named the research partner who had been involved and described involvement plans as follows:

*D1: He will also be involved in the phase 1 consensus group, analysing the phase 2 qualitative data, and disseminating the findings to a lay audience. His involvement will ensure that the research remains relevant to the end users and the patient perspective is incorporated at every stage.*

The paragraphs on involvement plans in the IRAS form (D2) and the protocol (D4) were very similar. The IRAS form included the intention to register the study on the INVOLVE database, but no entry was found.

When the study started in 2011 the chief investigator recruited two research partners. They were identified in discussions with other researchers and the involvement co-ordinator from a database of existing contacts. Two potential partners were contacted by the chief investigator and both agreed to contribute; one was experienced (RP1) and the other was new to the role (RP2). RP2 had asked about involvement opportunities at a clinical appointment. Further information about recruitment is in section 5.6.1.

### 5.2.2 Involvement in phase 1

Each of the research partners met separately with the chief investigator and research fellow prior to phase 1 data collection. The researchers wanted to ensure that research documents were user-friendly and that the consultation meetings they planned would work in practice. Involvement meetings included reviewing draft documents, discussing the agenda, arrangements for the meetings, and explanations for phase 1 participants.

*R2: we had.. the questionnaires which we were going to put to them to have a look at and a booklet which explains about how scales are developed.. we sat down with our two patient research partners at that point and asked them to look through.. the details*

*RP2: we spent some time ... talking about what might happen in an open meeting and it allowed [R1] to run through what she was going to say so it was like a dry run*

Following these meetings the research partners were sent revised materials for written comment.

In phase 1 all eighteen participants were recruited because they had experience of completing scales and measures as research participants, and of working as research partners on other studies in the department. This experience was seen as an important resource given the study's aim. The chief investigator reflected that it was probably the first time that an expert patient participant group had been chosen, which was described as a dual role. RP1 took part in phase 1 as a study participant alongside his role as research partner on the study.

*R1: it may be the first time ... that they have.. had that dual role of patient partner and participant at the same time*

*R2: .. getting someone who is very research naive to look at things which are ... quite complex ... the difference between various scales and various wordings.. it was very helpful to have that non-naive approach to it*

The outcome of phase 1 of the study was that participants did not assess existing measures as adequate so a new measure had to be developed. Potential wording for questions were reviewed and developed in phase 1, and the researchers then developed a set of draft questions for phase 2 of the study. Involvement experience was acknowledged as important.

### **5.2.3 Involvement in phase 2**

The draft wording and layout of questions were considered at a research team meeting in December 2011 attended by both research partners prior to phase 2 data collection. The minutes of this meeting (D12) provided a summary of contributions including nine attributed to research partners, which related both to the layout of the questions and to wording.

*D12: [RP1]: Timescale of "the last week" – not easy to relate to this, may be a month or even longer. Last 24 hours would be more specific.*

After this meeting the new measure was revised again for phase 2. When the focus groups with rheumatology patients from two hospital sites had been conducted and data analysed, another version of the outcome measure was developed and sent out to the research partners, with other research documents for phase 3 of the study, for their individual feedback by email and/or post. There was no research partner involvement in data analysis in phase 2.

### 5.2.4 Involvement in phase 3

Phase 3 piloted the use of the new questionnaire in comparison with existing validated questionnaires. Participants were patients from two hospitals; the questionnaires were completed when medication was changed (baseline) and at three month follow up. Once the measure was finalised after phase 2 there was no involvement of research partners during phase 3, when the chief investigator and research fellow concentrated on recruitment and follow up of phase 3 participants.

### 5.2.5 Involvement in analysis and dissemination

Following collection of data in phase 3 quantitative analysis was conducted; R1 reflected that involvement in analysis was dependent on the study methods, where quantitative analysis limited involvement.

*R1: I think involvement depends a lot on exactly what methods you are using ... and where I have had the most involvement in projects in the past .. is probably when they have been qualitative.. because they really get involved in the analysis [of interviews] and contribute so much ... and so if you have got a very quantitative study they can't get involved in the analysis*

Following researcher analysis of findings a draft article (D21) reporting findings was discussed at a research team meeting in January 2013. Neither RP2 nor the statistician could attend this meeting. Discussion was technical and RP1 contributed drawing on prior statistical knowledge, for example, commenting on the use of 'box and whisker plots' as visually unhelpful.

This excerpt shows the tone of discussion early in the meeting:

*RP1: yea I think coping can have.. not that much to do with severity of a disease.. myself.. and I notice from one of the.. in particular the graph.. I was a bit confused by it to be honest*  
*R1: oh right well we'll get there shall we*  
*R4: shall we have a quick look because I thought that was really interesting.. and he's just showing off that he has read the paper*  
*R5: whereas [R3] is still reading it as we speak*  
*R1: I know.. I thought he'd at least read it on the way to.. work as he is walking..*  
*General laughter*

At the meeting it was agreed that the findings would be reported in two separate papers, and discussions focused on what additional analyses might be done and how findings could best be presented. RP1 contributed more often to these discussions than two of the researchers present, but less often than R1, R3 and R4 who made most contributions. The chief investigator asked RP1 for suggestions about what findings and information might be of interest to study participants so that she could prepare a study summary for them. It was agreed that the chief investigator would draft this summary for comment by research partners.

*R1: very much guided by what he [RP1] was saying in that meeting about the coping aspect being really interesting*

Afterwards the chief investigator reflected that RP1's statistical knowledge had been very useful, and that it might have been more difficult to include RP2 in the meeting, had she been able to attend. Given journal requirements to declare the extent of author contributions, the chief investigator doubted whether the research partners would be able to be co-authors, but their contributions to the study would be acknowledged in articles.

### **5.2.6 Involvement role**

RP2 commented that when she was sent documents by email for comment she initially focused on layout because that was of interest to her; later she realised she could have spent more time on the content of questions. Contributing to her first study she wasn't completely clear what was wanted.

*RP2: when I read the things they sent by email because of my background I was more interested in the formatting ... and I didn't concentrate quite so much on the questions which was probably what I should have done ... .. I don't think in my mind I was clear on what they wanted*

Both researchers and research partners agreed that the core of the role of being a research partner was an ability to share experiences and views. Research partners needed a willingness to participate and sufficient confidence to speak; given this starting point confidence and understanding could be developed. However, some research partners acknowledged that talking about personal experiences could be demanding and not everyone was able to cope with personal disclosure.

*R4: I don't think the patients need any particular skills other than a willingness to participate and speak up*

*RP6: they might find it too stressful talking about themselves ... and basically that's what we do .. we talk about our experiences and not everybody can cope with that*

However, it was recognised that the role required some reading of research documents, particularly patient information sheets, and that research partners needed to be able to work in a team.

Senior researchers had envisaged a more formal system of involvement where research partners would have job descriptions, but over time both researchers and experienced research partners had agreed that this was likely to put patients off.

*R4: [in] the European guidelines which came out in 2011 ... we suggested that there should be a role description. The difficulty that we have is that quite a lot of people I think wouldn't take it on if they knew what they might end up doing.. because it sounds*

*too difficult.. so we do involve our patients in helping us analyse transcripts of qualitative data and they will come to that gradually during the project meetings and it is introduced more as .. well could you just have a look and circle what you think is important.. but I think those sorts of descriptions at the beginning .. saying oh you will be helping us analyse data ... is quite problematic and off-putting for some patients*

Neither of the research partners in the study knew what involvement jobs would be coming next when I interviewed them, but this was not seen as a problem. RP1 explained that he got on with his life without thinking about the study, or doing anything behind the scenes, but he would respond when the researchers got in touch with him.

Involvement processes described in section 5.4 below indicate some elements of the researcher role. In addition, several research partners felt the professionals had to be comfortable with involvement. Senior researchers in the department were seen as very good at talking to patients and making quite complex ideas accessible without being patronising.

*RP6: they are able to just make very difficult things accessible for those who have no background but also they don't give us more than we need, they don't go into it in such a complex way that we have to retain all that information ... it's simply about taking the mystique out of that particular topic ... so we've got a flavour of what they're talking about*

Some researchers and research partners noted that researchers needed to be aware of possible distress and be willing to check up on how research partners were after meetings if there had been any difficult discussions. This support role was not always necessary, but researcher awareness of the potential for involvement to trigger vulnerability or distress was important. Provision of support drew on clinical skills and care for research partners as both colleagues and patients.

*RP6: it is essential that somebody like the principal investigator picks up on what's going on during the meeting and how that might leave the patient research partner feeling.. and you know it is helpful to have contact afterwards. If they suspect that there has been a ... difficult area touched upon ... just to say are you okay with that? How do you feel? Just a kind of debrief. Not every meeting will do that but some meetings might just affect somebody*

### ***Navigating between roles***

One significant issue for both researchers and research partners was the move between being a patient and being a research partner; many of the research partners had been treated as patients by the researchers they worked with.

*RP5: Initially ... I felt a little bit ... oh she knows so much about me and I felt... I don't know what the word is ... not exposed but ... oh I wonder if everyone else knows everything about me ... but ... that must have been like an initial few minutes of*

*thought in my mind ... about how comfortable I was ... and trying to get used to seeing her as a different person as well as a nurse that treats me*

*RP6: So actually being involved in the research and seeing people outside of clinic and being able to talk openly about the difficulty of seeing somebody in clinic in one minute and then in a completely different setting and not knowing how you refer to them.. we talked openly about that and kind of cleared the air and were able to pull up the barriers that were needed to ... I say compartmentalising the two roles ... you have to have a barrier. You have to say in clinic it is just a doctor/patient relationship and that's it ... and outside of that I'm not a patient, so outside of the clinic I am me*

Similar boundaries needed to be in place in the patient advisory group; in meetings patients did not share personal experiences, but they did while having lunch together beforehand. Managing boundary issues was described as a learning process for researchers and research partners, and both groups had helped to develop ways of managing this process.

*RP4: I remember the meeting quite vividly, we had an important meeting about relationships and feelings and working with different people ... what we felt was that with people like [R3] or [R4] .. when we were in clinic .. we were the patient ... but when we were there [research meetings] then we felt quite at ease because they made us feel at ease just to be colleagues .. and [R3] said well you have actually made it easy for us because we were worried about the blurring of the lines .. but he said this is fine ... you have made it easy for us. It's just become such a nice working relationship all round really*

Most research partners were comfortable to be on first name terms with health professionals when they were involved in research, although this did not necessarily include being on first name terms for appointments as patients. However, one was not comfortable in calling R3 by his first name in research meetings although R4's first name was used.

### **5.3 Impact of involvement**

In this section impacts are described on research processes and on people; in addition data related to cumulative impact across the department are reported.

#### **5.3.1 Impact on research processes**

The chief investigator and research fellow both reported impacts on research processes. This included improved wording of the lay summary in the funding bid, on study documentation and on the practicalities of running the study. In particular, research partners made a difference to the wording and layout of information for study participants in phase 1 and in the wording and layout of the measures themselves. Research partners also had an impact on the practical arrangements for phase 1 data collection.



*R1: it was really about making the research as accessible as possible.. through making sure the information sheets were good ... trying to improve the layout of questionnaires.. more practical things*

Development of the outcome measure was an iterative process, and incremental changes were made following phase 1 data collection, at a research team meeting, and following phase 2 data collection. Research partner input on the wording and layout of the outcome measure overlapped with input from research participants on these issues, this made specific impacts of involvement difficult to distinguish in a many staged process.

The chief investigator drafted a summary of study findings for research participants at the end of my data collection period, it was sent out to both research partners by email who gave feedback.

### ***Difficulty in identifying and assessing impact***

RP2 did not know if she had made a difference.

*RP2: I can't see that I have made a difference but I hope I have.*

However, for RP1, experience in the department over time had confirmed that overall involvement made a difference.

*RP1: I am more confident now ... that the involvement of patients is contributing to research and contributing to the various projects ... yes*

The involvement co-ordinator had created a form (D13) to report impact with the support of the head of department and consultant nurse, but it had not been well used.

*RP3: I've got a couple of feedback forms ... [but] it's hard... to get that in*

*R1: I think it's really hard to actually track the impact .. [RP3] keeps .. emailing us every so often with a form saying please .. [laughs] any time you can see a tangible impact write it down and send it to me.... but it's really hard to do that*

The chief investigator tried to keep track of impact by recording contributions as they were made, and notes of a meeting (D12) documented contributions from research partners.

However, because research partners were seen as integral members of research teams their contributions became part of the ongoing group process, and were therefore more difficult to identify.

*R4: actually it's really hard to pick out ... something specific because ... it's so much integrated into what you do that you actually don't notice it ... it's just a team discussion*

Reflecting on the impact of involvement in research in the department over time, researchers reported that occasionally impact was memorable but often it made more subtle differences.

However, systematic involvement created conditions which maximised opportunities for involvement to have a significant impact.

*RP4: there are some times when you do remember specific things because it.. changes something very significantly ... so in another study ... we were looking at fatigue ... we were planning to recruit patients with active disease because they would be tired and it was our patient partner who said why aren't you recruiting people whose disease is quiet ... we said because they won't have fatigue and she said that's not true my fatigue is as bad whether I have disease activity or not ... so that made us change our study design.. so that really stuck in my mind*

During the interview, the head of department realised that although there had not been involvement in developing some conceptual thinking, in fact it had been influenced by research partner contributions.

*RP3: I hadn't really thought about it that way before ... there wasn't a patient in the room when we thought about that.. and there isn't a patient co-author on the paper ... but actually now that I think about it .. we would never have looked at it that way if we hadn't had quite extensive interactions with patient research partners.. during the work*

### **5.3.2 Impact on research partners and researchers**

While RP1 had been involved in the department for many years, this was the first experience of involvement for RP2. Both reported satisfaction in helping with the study and were pleased to be giving something back to the department. No negative effects were reported.

*RP1: I think the involvement perhaps helps you a little bit in thinking ... somebody's taking notice of you ... you are giving something back ... you felt you mattered, you weren't just coming here as a patient you were doing something and making a contribution*

However, over time both researchers and research partners reported both positive and negative impacts on research partners.

#### ***Positive effects for research partners over time***

Positive effects on research partners were described as enjoyment and increasing confidence in the role, alongside broader positive effects on life, including providing meaningful occupation, pride in contributions, coping with the condition better, and positive changes to self-esteem and identity.

*RP3: I've enjoyed it. It's been good really because having [RA]... it knocks the confidence out of you ... they've sort of brought me out into the role as well*

*RP4: it's helped me cope actually and I have made lots of friends*

*RP3: it has been a really really gratifying unexpected outcome of involving patients ... the number of patients who have been involved who have said this has changed my life*

*... .. the other thing that patient research partners tell me is that they learn to cope with their condition better ... that is a totally unintended consequence*

All six research partner participants reported positive benefits from involvement in research and from other involvement in the department. One research partner reported that involvement had helped her feel less alone with the condition, and another felt involvement had shifted her identity from feeling she had become 'just a patient' to a recovered sense of self as a person and colleague.

*RP6: in clinic it is just a doctor/patient relationship and that's it and outside of that I'm not a patient, so outside of the clinic I am me, I am [name].. and I no longer feel that I am patient and I think for me that's been one of the big ... benefits of being involved that I.. emotionally ... in my head now don't refer to myself as a patient ... .. you lose your sense of self but it takes time and then... the same process... over time I found myself again ... for me that was a big benefit of being involved as a research partner and being able to make that transition from patient to person, partner, colleague*

The two research partners with most experience of involvement in the department reported that there had been many positive involvement experiences and personal benefits over the years, including going to international conferences and working on national guidelines.

### ***Negative effects on research partners over time***

Some negative experiences were reported, both researchers and research partners reported similar issues, which included patients finding out information about their condition which triggered unwelcome awareness and distress.

*RP3: I've been to lectures that.. make you face up to some of your RA [rheumatoid arthritis] things ... you might see pictures of joints or deformity that are quite shocking and it comes upon you suddenly ... you wouldn't normally see that as a patient and that can be a little bit harder to take, you think oh crumbs.. what's in the future?*

Sharing experiences could also be painful.

*RP6: you have to talk about things which you feel quite vulnerable about, you know how the condition is affecting you emotionally, how it's affecting your family, all those kind of things.. it can be quite hard*

While the majority of involvement experiences were positive there were some negative effects.

### ***Impact on researchers***

The chief investigator reported that having a research partner involved in her doctoral research when she first joined the department was invaluable, she did not know anything about rheumatology and had gained much more understanding from the research partner than from observing clinics or talking to health professionals. Researchers reported that

involvement motivated them and reinforced awareness of the importance of research for patients. Researchers also understood the importance of experiential knowledge and how involvement shifted values.

*R1: so you have not just got the clinical expertise.. but actually the direct.. experiential knowledge ... it becomes harder to not value that input in other ways ... and once you have a really successful example ... that can't help but change your values*

*R2: it gives me that human face and that incentive sometimes to .. get beyond the facts and figures .. and to actually look at the person below and I think that is a really big issue for me as a researcher to keep that as my focus ... you can get very entrenched in numbers and trying to prove things ... but you know the bottom line is that we are there for the patients*

### **5.3.3 Cumulative impact**

The established practice of involvement over time was described as having significant impacts on relationships between patients and professionals, on clinical care and on research. These impacts were mutually reinforcing and cumulative. Research partners felt it was easier to get involved in research because staff were committed to, and experienced in, involvement.

*RP6: research in the academic team is one major aspect but with the nursing staff, with the physios, the OTs ... they're just used to a different ... relationship with their patients than you'd find in other areas. So it's a very friendly, open department ... so I think the patient experience is different*

Having patients involved in research had led to improvements in care, for example, patients had identified a need for more focus on foot problems and this had led to both initiation of research and the introduction of a foot clinic, so access to treatment had changed alongside the potential for longer-term benefits from research.

*RP6: a lot of the research you do it's over a long term ... it's not just that you've got the three years of the project, it's then how long is it going to be before it has an impact and that could be a long, long time .. and also it might just be part of a body of work that eventually has an impact. But there are some things which I've been able to see almost immediate impact and that's been super, one was in the area of feet ... not only did it sort of take-off and people started doing research.. but almost immediately [R3] introduced a clinic in the department which looked at feet ... a combined clinic with an orthotist, a podiatrist and him as a rheumatologist. So immediately the .. access to treatment changed ... looking at RA patients' feet and how they could be helped to not get the damage that I've got. It was super and to see that research was going to benefit in the long term but also for the department we have an immediate impact, it's great*

The head of department particularly emphasised the identification by patients of fatigue as a whole new area of research.

*R3: one really concrete example ... fatigue as an important outcome in rheumatoid arthritis had been ignored for 25 years and it wasn't until patients started saying this is really important to us.. [R4] picked up on this first.. I worked with her.. but she was the lead on this ... and then we have started a whole programme of work.. which has resulted in ... an international decision that you should measure fatigue in all trials of new treatments in rheumatoid arthritis and ... the development of a new questionnaire to do that .. and that questionnaire is currently being translated into 38 different languages and has been cross validated in these languages.. and is now being used all over the place ... .. all this ... on the basis of responding to patients telling us that we had missed something ... it's almost like a new industry of measuring fatigue in rheumatoid arthritis.. and it has knock on effects for other conditions too.. so people are also starting to measure fatigue in other conditions as well*

Development of involvement at an international conference had also resulted in significant and unpredictable impacts. A snowball effect was described, for example, influence on another European initiative included commitment to patient involvement in agreement of clinical guidelines.

*R3: [Conference name] will not approve any core set of outcome measures for any condition unless patients have been involved in developing it ... that rule was agreed two years ago ... I mean .. these are astonishing changes .. unpredictable from 10 years ago*

These impacts were seen as the payoff for long-term commitment to involvement.

## **5.4 Processes, mechanisms and resources**

This section presents findings which relate to how involvement was conducted, including significant involvement processes and mechanisms. Mechanisms include the way that involvement was conducted and other practicalities, like payment and training. This section concludes with findings on resources for involvement.

### **5.4.1 Important involvement processes**

A number of factors were identified as important to support research partner involvement in the study and department. Three of these four factors were both observed and reported in interviews (starred below), developing confidence and understanding was only reported in interviews.

- Welcome and appreciation\*
- Developing confidence and understanding
- Encouragement in meetings\*
- Feedback\*.

### ***Welcome and appreciation***

It was important to be welcomed into a friendly environment; all research partners reported that the department was friendly both in the clinic and in research. RP2 linked the friendliness in the clinic to her experience of getting involved in research.

*RP2: that service, that friendliness, that approachability, is what makes it easier to do the research and help in that area ... the clinics and that whole area are staffed with people who smile at you and are approachable*

*RP2: I wasn't really sure what to expect.. but what I have met is professional people who were very concerned and ... very kind and very welcoming ... and I couldn't have had a better introduction*

At the beginning of the January 2013 team meeting the chief investigator was there early to welcome RP1 and he was included in informal conversations, afterwards R1 also stayed on to talk informally and thank him for taking part.

*Field note: The atmosphere at the beginning was friendly and welcoming, RP1 was definitely included in the conversations in fact he was the focus of the conversation to some extent. This felt like a norm of hospitality and welcome, reflecting my own experience of coming here.*

A friendly welcome and being appreciated was the foundation of support.

### ***Developing confidence and understanding***

All experienced research partners reported anxieties in relation to their first experiences of involvement in the department, and that it took time to contribute.

*RP1: I think when I first went into a meeting I thought well ... am I going to be able to help in any way.. am I going to be able to contribute ... I don't want them all talking about medical terms above my head*

*RP6: I just thought oh I don't think I can do that ... feeling as though I didn't have anything to contribute and not knowing what I could do ... I didn't know anything about research*

RP2 reported similar feelings; she had found it easy to contribute when she met with the chief investigator and research fellow, they were described as encouraging and open. It was more challenging in the team meeting, which she described as like coming in half way through a theatre performance where everyone else knew the story.

*RP2: Sitting in a room full of people with very definite opinions who are pros in this and.. not quite knowing.. feeling your way along ... .. I was a little overawed ... yes I felt out of my depth ... feeling oh my goodness what am I doing here?*

RP2 was pleased that RP1 was there, he was contributing ideas and being taken seriously and his presence as a confident patient helped. RP2 said that having a short précis of the study

and role would have helped at the beginning, and more reassurance about the value of her contribution. RP2 had not been able to meet the involvement co-ordinator prior to starting on the study, although this was normal practice, so she had missed out on this additional induction and support.

Research partners reported that confidence built over time and as relationships developed. One research partner felt confident to ask for opportunities.

*RP1: ... initially [at] the first meeting I don't necessarily ask too much ... and only perhaps when you become comfortable with the people you do*

*RP5: years ago I would never have picked up the phone and asked to do something ... I just waited for them to give me something*

One of the researchers also commented that that it took research partners time to speak out in team meetings, and that it was easier to share experiences in one to one meetings.

Developing confidence was also related to receiving information. When the research partners were recruited the researchers had provided written information about the study including the protocol. RP2 would have liked more opportunity to ask questions about the documents she received.

*RP2: .. I think I might have liked to have asked a few questions to qualify one or two things ... sometimes they [documents] have jargon in them but on the whole I think I managed to get through it and come out with something I understood.*

Provision of information was important for other research partners at the start of a study.

*RP5: she was very good at relaying information to me and telling me what she wanted to achieve with her research .... she did also send me some information ... before I met with her ... and that was really helpful to me so I didn't go in cold*

RP1 had no problems in contributing, but RP2 felt that involvement in the team meeting was more demanding than expected.

*RP2: when it came down to it ... it wasn't as informal and as low level ... I thought they would just gather patients together and have a little chat with them and see what they felt.. I didn't expect the meetings we have had with senior members of staff where our views were probably on a par with theirs.*

### ***Encouragement in meetings***

A key way in which research partner contributions and understanding were supported in research meetings was through good facilitation from lead researchers.

*R4: the principal investigator ... may have to be more proactive in the beginning.. so asking people specifically what their experience is.. that gives a clear message to other people on the team that they can't talk over the patient partner, or talk amongst*

*themselves, and assume the patient partner doesn't understand or doesn't need to understand.. so a principal investigator needs to be explaining acronyms or terms that come up ... I think the principal investigator is key to making it happen, and if they don't do it properly then it does become tokenism and they can very easily block the patient from speaking*

The head of department reflected that meetings might take longer but that researchers also sometimes benefitted from explanations provided for research partners; while researchers might be reluctant to ask questions, research partners were encouraged to ask questions all the time.

*R3: people used to look at us and say ... don't the meetings go slower ... they do go slower yes.. because you have to make sure that everybody understands.. but the other side of the coin is actually ... everybody at the meeting understands what is going on ... the number of people who sit in meetings .. and don't grasp what is said but don't like to ask questions in case they feel stupid*

Facilitating involvement required adjustment of meeting norms to accommodate research partners, and researchers needed to combine facilitation of involvement with leadership of research meetings, and contributing based on clinical and/or academic expertise.

*R1: a meeting has quite a different flavour when there are the partners there ... you have got to have that sort of awareness of ... being inclusive so you keep checking that people are following*

The chief investigator felt it was important for researchers to stay open and really explore partner experiences without making assumptions.

*R1: one of the main things ... is just to maintain openness ... just to keep questioning everything.. and really interrogating what people are saying rather than starting to make assumptions ... always try and keep teasing it apart and checking what you think they are saying*

Providing reminders for research partners about the study and progress at the start of meetings, and whenever there had been gaps in involvement was also seen as important. At the start of the January 2013 team meeting R3 asked the chief investigator for a reminder about the phases of the study, which was potentially helpful for all team members and in particular for RP1. The involvement co-ordinator also identified the need for reminders.

*RP3: ... as a patient partner you're not living it every day like the research team ... and you forget so... [researcher] sometimes will phone people up .. the day before the meeting and ... say what we are going to discuss and that's quite beneficial ... because ... it focuses you back into it beforehand ... so you're not spending the first half-hour [thinking] what's it about again? ... it's really good just to have that refresher contact beforehand*

Despite awareness of these needs and support from researchers, RP2 reported it was quite a challenge to take part in the first team meeting.



*I: it sounds as if in that meeting it was a bit more difficult for you ... ?*  
*RP2: Yes I felt out of my depth*  
*... I: did anyone ..turn to you and say what do you think?*  
*RP2: Yes they did.*  
*I: .. so there was some encouragement?*  
*RP2: oh yes.. yes... I think it was me .. you know feeling oh my goodness what am I doing here*

All the experienced research partners reported that they had been encouraged and supported to contribute to meetings by researchers in the department.

*RP5: right from the start ... I can remember [two researchers' names] especially saying did you understand that? And oh that word meant such and such ... and they did kind of keep an eye on me that I was following everything ... it was very welcoming and very open to me and everyone equally participated*

In the team meeting in January 2013 there were many examples of supportive facilitation from R1, R3 and R4 and RP1 asked several questions.

*R4: sorry [RP1] do you know what cognitive interviewing is? It is when you get someone to fill out the questionnaire and talk aloud and you are trying to see*  
*RP1: oh I see*  
*R4: with the question ... did they understand the word in the way that we meant it to be understood*  
*RP1: right*  
*R4: or can they not answer it because the response options are stupid*

The facilitation of involvement meetings by senior researchers and principal investigators was an important way that active leadership was demonstrated, and reports by experienced research partners suggested that this kind of leadership had contributed to the development of the culture of involvement.

### ***Feedback***

It was important for research partners to get feedback from researchers about involvement, including updates and impact. It was important to know if involvement had made a difference, and/or why ideas could not be taken on board.

*RP1: have you made a difference .. it is lovely if you find out yes you have! Or perhaps explain why something you said or suggested or whatever ... why they thought we wouldn't go down that route*

*RP5: it is important ... to be kept up to speed with what is happening as well ... it is quite nice to see what becomes of something you've been involved in*

### ***Building positive relationships***

These involvement processes contributed to building positive working relationships between researchers and research partners, and the development of confidence over time.

*R5: what seems to happen ... is there is an education process going on at the same time so as people are contributing they are also learning ... and in a way what you see is that they become more confident*

*RP6: it's those kind of things ... it's the training day, seeing people out of the clinic context, building up a rapport, helping people to feel comfortable, encouraging them, giving them feedback ... all enable people to feel able to say what they really want to say in a meeting.*

One of the experienced research partners summed up the process she had been through as follows:

*RP6: they made that engagement very easy ... an easy transition. And it also showed me that actually the researchers, whilst I assumed that they would know everything there was to know about RA [rheumatoid arthritis], there was actually quite a lot of gaps. So that was good, they were also very good at giving feedback and helping you with confidence and ... helping facilitate my engagement. ... So that was my first project and it went on from there really*

#### **5.4.2 Involvement mechanisms**

The two research partners were members of the research team and this meant that they attended research management meetings and were included in all routine emails. As well as contributing to meetings, they met with the chief investigator and research fellow separately on two occasions, and contributed by email, post and telephone. Involvement took place occasionally in relation to phases of the study and specific involvement tasks.

Most research partners in the department were involved in this way, with an aim to involve two research partners in each study, often one experienced and one new, to support those new to the role and to ensure a contribution if one person was ill or not available.

*R4: So very often it's worth having two patients partly because they bring different skills.. and different ideas and experiences, but also because we are interacting with people with a variable condition.. if one of them has a bad patch and can't attend three meetings in a row.. you still have your patient input from the other partner*

The department employed a research partner as a co-ordinator to support involvement in research, this position had been developed as involvement in research grew and it was harder for researchers to manage the work. RP3 had been in the post since 2008, and her predecessor, RP6 (who took on the role on a voluntary basis) acted as a mentor when RP3 took over. RP3 was paid for 5 hours a week on a flexible basis, but did extra work from home, in particular checking and responding to emails.

*RP6: So [R3] arranged to have somebody go in and help out on a voluntary basis to ... co-ordinate the training programmes.. to support the patients and to make contact with the patients. So I did that initially*

The co-ordinator was a contact for research partners, and kept a database of contact details, medical conditions, what days people were available and how best to communicate with them. There were about 30 research partners on the database, some contributed regularly, and others less frequently or rarely. The only form used systematically was a confidentiality form, but it was possible to arrange a university email account and library access if needed.

The co-ordinator usually met with new research partners informally for induction, encouragement and support; explaining what research meetings were like, what they would be asked to do and how the role differed from being a patient. She would also attend initial meetings between researchers and new partners.

*RP3: I like to get people comfortable in their role that's my agenda really, so not intimidated.. [so] they feel supported that I'm here*

Several participants noted that having a research partner working in the offices as a colleague made a difference; different relationships were developed and this was linked to a change in the department's atmosphere. R2 described working in this way as inspiring.

### ***Learning and development***

The co-ordinator arranged training days for research partners, usually every other year, which was a chance for them to meet as a group. I attended a training day for research partners in September 2012, but neither RP1 nor RP2 attended. The head of department was present all day and the consultant nurse was there all morning. There were four different sessions about involvement in research, with lots of breaks and lunch was provided. Research partners sat together at small tables of three or four and the day was characterised by lively participation and discussions and warm relationships between researchers and research partners were evident.

*RP6: one of my first roles in that ... particular position [co-ordinator] ... was to set up the next training programme ... one of the things I have done at [conference name] is to introduce the training days and make sure that they have training days before the start of every one*

### **5.4.3 Resources for involvement**

The department paid the involvement co-ordinator one day a week and provided a desk, computer and other resources for the role, including payment of travel expenses. The head of department was clear that resources needed to be committed to ensure continuity, as an investment for long-term return, and to institutionalise arrangements. He compared paying the co-ordinator to ensuring that there was a patient education programme running in the department by providing specific resources which ensured ongoing provision.

*R3: to think that it happens for no input is a mistake ... so you have to be engaged with it without running it*

*R3: I realised that because the number of patients we were getting involved here was increasing, and because things like running our patient training days and keeping track of everybody and .. looking for more patients, new patients .. to be involved in new projects .. as they came along.. was just beginning to get too much of a job for us just to do on the side*

In addition, leadership and departmental norms supported the allocation of researcher time to involvement. Involvement was routine and embedded in role expectations for researchers, and researcher time spent on involvement was the main resource.

### ***Payment and reward***

The department did not pay patients for their involvement but travel expenses were covered. This reflected the evolution of involvement in the hospital where there were many unpaid volunteers, and in service development and teaching as well as in research. Many patients were on benefits which made it difficult to receive payment. While some research funders did provide resources for payment this was not reported as the norm. The two research partners were not paid, but all expert patient participants in phase 1 were offered shopping vouchers.

*R1: it was the first time that a lot of them have received something like a voucher ... I had to be very clear that we can't always offer this ... I got the feeling that they ... felt more able to take a voucher than ... a payment that would have come through the university.. so it was quite interesting to consider.. if you do really want people to accept it maybe it is better to consider vouchers*

Both researchers and research partners expressed mixed feelings about the issue of payment. Some staff worked for a university which had a policy to pay for involvement, so if a study was run by that university research partners were paid; this created a complicated situation in the department.

*R3: I am biased towards not paying.. like we don't pay for blood donors, right.. I think [R4's] a bit biased towards paying, but she is employed by an institution that says that that's the policy ... my own view is that patients come as volunteers*

*R4: everybody else around the table is paid to be there, and I think he [R3] feels that they are doing voluntary work ... but I think they should be offered the opportunity and if they want to accept it that's great, and if they want to say no I'm doing this as voluntary work, that's fine as well.. but I think that's not my decision [but] at the moment it's more of a government decision isn't it as to whether or not they can take it*

Research partners reported that they did not mind contributing without payment, but several wondered if it might be an issue for others, and noted that everyone else was paid. Both researchers and research partners were very aware of the difficulties caused by benefits

regulations. One research partner wondered how easy it was for people to say they would like to be paid in an environment where most were not paid.

*RP5: I've got mixed feelings about it really.. I suppose I would like to be paid, but it would affect my benefits so ... I don't really have much choice about it ... maybe something like giving people a voucher is a really nice idea ... but that said, I'm still happy to do all this and not be paid because it's something that I feel passionate about*

*RP6: I don't see that you can put a value on having lived with something 24 hours a day for decades and say well this is worth this much so I struggle a bit with that*

While travel expenses were always available it was reported that often research partners did not claim expenses, however RP2 did claim travel costs. The chief investigator and involvement co-ordinator were both clear that research partners needed to be explicitly encouraged to claim expenses, particularly if some of their peers did not, and that payment to individuals needed to be discrete.

However, there were other forms of reward for involvement, including the positive benefits described earlier. Some research partners had contributed to journal articles as co-authors (RP6 had contributed to 22 peer reviewed articles) and some had the opportunity to attend conferences, including international conferences, funded by the department.

## **5.5 Context of involvement**

The head of department took over in 1987 and there had been involvement in the patient clinic since that time. He commented that they had had involvement in developing the patient education programme in the early days, and that the department had grown up with the idea that patients were part of the team of care delivery.

*R3: this [department] was formed 25 years ago this year.. we have probably had a formal patient advisory group meeting for 20 years..*

*R3: the roots of the patient involvement in research are set in the fact that patients were involved in the whole .. way we do things round here.. and then that naturally moved into research ..*

Treatment and care of patients in the department included a focus on supporting the self-management of conditions with life-long and disabling implications for patients. Once patients were diagnosed they required long-term treatment and care, and this meant that health professionals and patients were involved in long-term relationships.

### **5.5.1 Leadership**

The head of department and consultant nurse had both been in the department for over 20 years and were also the research leads. Their leadership was a key factor in the development

of involvement and the ethos of the department more broadly. The head of department had supervised the consultant nurse's PhD and she reflected on their relationship, saying they had:

*R4: been married for a long time [laughing] ... that's what it feels like ... yea being married*

Leadership included a long-term vision for the department focused on a clinic providing multi-disciplinary services to patients in one location, linked to research.

*R3: when the opportunity to get this local space came I argued really really strongly with the chief executive.. that this made us a better integrated unit.. and we also have our own physiotherapy, our own occupational therapy down here in the [department] not in the central space ... so persistent long range planning and taking opportunities as they arose has put us all close together.. and so this integration of two universities and a clinical service is.. I can't say it was planned each detail ... but this objective was in our minds 25 years ago ... and was effectively implemented fifteen years ago*

While leadership was a key factor, the nature of rheumatology had contributed, and the responsiveness of staff.

*R3: the whole atmosphere of the place has always been patient oriented, the way we deliver our services, our specialty, rheumatology, is a patient oriented specialty .. the team of clinicians who deliver services has always been a multidisciplinary team ... it has never been the doctors decide what to do and then everybody else does it.. it has always been a collaborative approach to patient management ...*

*R3: so there is no doubt, it would be foolish to say otherwise, that leadership is central to ... development, but you also have to have the response amongst people as well ... we are just surrounded by good people*

The head of department felt that involvement in research would only work if principal investigators were committed to it, without this leadership efforts by other researchers were likely to be more limited.

*R3: I have really noticed that moderately senior researchers can't get anywhere with involving patients because their PI.. says yea you can do it if you like .. but yea you can do it if you like isn't good enough, the PI actually has to actually invest time and effort into it to get the pay off*

Ongoing leadership and commitment to involvement was demonstrated when both leaders were present at the training day for research partners. When I asked why involvement had developed in this department R3 said:

*R3: we were the right sort of people in the right place at the right time ... I have got an unusual background in medicine ... and I have a natural ability to talk to people from all walks of life which a lot of my colleagues don't have because they have got limited experiences in their own life .. [R4's] route to her professorship is extremely unusual and takes in a whole variety of different experiences that she has had ... so she has got a very wide view.. and the fact that both of us happen to be in the same place*

Both leaders linked the development and consolidation of involvement in research in the department with their support for patient involvement in one international research conference in their field. The two initiatives became mutually reinforcing.

*R4: when we came back [from the conference] we started saying to the English patients ... that had come with us ... how can we take this forward, let's start working on this.. and they were just included.. and then it became more of a deliberate policy as the years went on*

*R3: what we were doing locally became much more ingrained in what we were doing because of the way we were also trying to promote patient involvement in [conference name] as well and.. the two things fed off each other.. we were using our local patients to help [conference name] ... the two chairmen of the patient group that we have had so far have both been from [city] ... so patient involvement has been run out of [city] for 10 years*

The influence of leadership on involvement was recognised by other participants, both researchers and research partners.

*RP6: You have to have people at the top who are committed.. to involving patients in all aspects and you've got two very committed people there .. in [R3] and [R4], and they made it happen but they also built in a culture where even if they're not there it would still happen because that's how people work now and they wouldn't see anything different*

The continuity of leadership and long-term health professional/patient relationships provided a fertile ground for involvement in research within a broader context of shared decision making in patient care, and involvement in service delivery and teaching.

### ***Patient leaders***

Two of the patients who had been involved in the department for many years also had leadership roles. This included lobbying the hospital for the department, involvement in the development of national clinical guidelines, and leading involvement at the international research conference. RP6 had been particularly involved in the development of training for research partners in the department and at the international conference.

The League of Friends in the hospital had specific money for rheumatology, and this money had been used to support the department.

*RP4:.. so I have been able to influence some of the things that we bought them.. a scanner ... the chairs in the day ward ... so I have been on that .. keeping an eye on what we have got left .. so that we can use it when we go to the new building .. because it's for the benefit of patients so anything that the NHS won't provide ... hopefully we can*

### 5.5.2 Patient oriented research focus

Research in the department was described as clinically focused, where research interests developed partly in response to patient views. This also reinforced the ethos of involvement.

*R4: we had the background of a focus that was very much around the personal impact rather than for example doing research on drug trials, we were much more doing home grown research about symptoms and self-management*

*R3: as our research interests overlapped more and more with patient reported outcomes then the amount of patient involvement.. became more just because that was where our research was ... and to some extent to be honest, the research moved in that direction because patients were telling us that that was what they needed us to do*

The focus of research linked to patient perspectives was demonstrated in the text of the protocol (D4) and in the research design of the study.

*D4: The growing literature on the patient perspective has revealed two important issues. First, clinicians and patients have different perspectives on outcomes. Second, patients prioritise treatment outcomes that are not routinely measured, such as well-being, normality and sleep, which may relate to disease activity.*

### 5.5.3 History of involvement

As a result of long-term leadership the department had strong norms of involvement. It was described as a culture where everyone worked together to improve the lives of patients, where everyone was on the same side.

*RP6: on the whole there isn't much of a 'them and us' culture, the dynamics are very much it's a 'we', we are all in it together ... you're in it because you want the best, you want to receive the best or you want to give the best and you do that together*

*RP2: I think the whole ethos of the rheumatology clinic is friendliness, professionalism and interacting with the patients ...you would be very unlucky to go to the other side, to research .. and people are totally different .. they say it comes from the top down so if ... the consultants are approachable I think it spreads out*

*RP4: the ethos and the atmosphere of this place is a lifeline when you have got a long term condition*

*RP6: when you have a culture as there is in the department now .. which is very patient focused, which is not just about treating the patients but listening to the patients, then that changes the culture. You know if you're willing to listen to a patient in a research meeting or a Patient Advisory Group then you're more willing to listen to them in the clinic as well*

All the research partner participants described their experiences in the clinic in positive terms, characterised by friendly professionalism and approachable staff, and most described the wish to give something back by getting involved. Self-management and shared decision making were described as part of the ethos, and having patients alongside staff in the offices was felt



to change the atmosphere because staff got used to seeing patients as colleagues and relating to them in a different way.

*RP6: just having that presence and people seeing you know the doctors and the other staff seeing a patient kind of wandering around the building, popping in to make a coffee, just all those normal [things] ... seeing people in the corridor, attending meetings, attending the postgrad sessions, so there is a patient presence. Apart from anything you might say, you don't have to say anything, you're just there and that over time changes the culture, it is a case of helping people just to get used to seeing their patients as people in the department .. and I think that was quite a good thing.*

*R4: I think it's a very powerful argument ... nothing about us without us ... on a clinical level it is something that we pursue very strongly particularly in long terms conditions where the patient needs to self-manage ... if you're an enlightened practitioner you no longer tell people what to do.. you negotiate with them what their options are.. and how they feel about each one and what might work for them ... and that has changed from the old paternalistic view of the doctor says and you do.. so there is no reason why that shouldn't creep into research as well.. and I think it is*

*R1: it links with how the patients are included in teaching the medical students or the Patient Advisory Group so.. it's not just about the research.. it is about the practice as well*

While these data reflect the views of those actively involved in the department, the open day was attended by about 60 people (my estimate) at least half of whom were patients. My perception of patient-professional relations at this event supported this positive view of relationships in the department.

*Department open day: [the event] feels friendly, a bit like a family, lot of interest and connection, people talking to each other. I felt moved and quite tearful several times .. something about this is what I'd like all the NHS to be like.*

The proximity of researchers to the clinical service, and shared clinical and research leadership, supported researcher access to patients as research participants, where researchers felt linked to service provision. Researchers could go to meet patients easily when they were attending appointments in the clinic, and researchers attended postgraduate teaching sessions which prompted research ideas.

### ***Involvement in research***

Involvement in research was embedded; research partners were routinely involved in writing grant applications and as members of research teams. A commitment to involvement by both leaders made it a guiding principle for all research.

*R4: because we drive the research and therefore because we say that this is how it has to be.. then that is how it has to be ... and because we both have the same views there is no escaping it*

The cumulative effect of involvement had resulted in shared learning, for example patient information sheets were short and accessible; so learning from research partners had become a departmental norm. An understanding of the long-term benefits of involvement was shared; the research fellow commented that seeing research put into practice in the department made her work feel more valuable and gave her a sense of pride. The chief investigator expressed commitment to involvement, reporting that it was a fantastic way of working that made complete sense, and that if she moved to another department she would want to set up a similar system. Despite time pressures at the end of the study, she produced a summary of findings for participants, and aspired to involve research partners in the collection of interview data.

*R1: it's so important ... for me sending out a summary of results to participants is really, really important and I know most researchers don't do that*

In the department research staff were recruited who were prepared to involve patients, and there was involvement in all PhD supervision teams.

*R3: I guess that is an unwritten rule.. when we appoint researchers .. you can only get a job here if you are going to be prepared to work with patients ... that is not written down anywhere .. but ... the whole way we talk about it makes that clear*

*R3: our PhD students have all got patient partners ... where's that in the PhD regulations? Well it isn't anywhere, but that's what we do*

R5 was not based in the department and she reflected that in her experience there research partners were active members of research teams, and she described the relationships she witnessed as true partnerships. The head of department reflected that he had seen a significant benefit from involvement beyond his own research and that they had been working in this way long before involvement became fashionable or endorsed by policy.

### ***Involvement in patient care***

Clinical staff were also recruited based on willingness to involve patients, and doctors were contractually required to accept a patient self-referral system. There were many examples of involvement in the development of services and patient care over many years, including the implementation of a direct access system for appointments; RP1 had been very involved in its development.

*RP4: there's about 800 of us now I think on the direct access.. which is brilliant because it means you are seen when you need to be seen and not when you don't*

The patient advisory group had about 35 members, with up to twenty patients attending each meeting. This group was informal, produced a newsletter and helped to run open days as well

as contributing on issues related to patient care. RP4 chaired this group and health professionals attended each meeting. RP4 had been involved with other patients in lobbying the hospital on behalf of the department, reporting a number of 'battles' being fought, including keeping a room for the patient education programme; these contributions were orchestrated by the head of department. Patients also were involved as teaching partners, helping to train doctors in student exams, and contributing to nurse training sessions at one of the universities.

## **5.6 Who was involved**

This section presents findings about how research partners were recruited, and issues relating to legitimacy and representation.

### **5.6.1 Recruitment**

Research partners had been recruited in two main ways. In the past departmental open days for patients and the public had included talks about research and patients were invited to get involved at these events. More recently, health professionals identified patients who they thought might be interested, and passed names on to the involvement co-ordinator; when new studies were planned they would be contacted and invited to contribute. In addition, patients with particular conditions were identified and approached for specific studies. Two of the research partners felt it was most successful and encouraging to invite people to contribute. There were no problems in identifying and recruiting patients for involvement because some researchers were also health professionals, academic researchers shared offices with health professional colleagues, and they were all located next to the patient clinic. Researchers also identified potential research partners from their research participants.

The qualities associated with selection for involvement were asking questions about different treatments and coping strategies and a capacity to reflect on different perspectives. When identifying specific research partners for a study, researchers and health professionals had discussions about who might be appropriate and available; these discussions sometimes included the involvement co-ordinator. Perceived personal benefit of getting involved was not a primary criterion for recruitment by researchers.

*R4: I don't think that we would ever primarily ask a patient partner to join us in order to benefit them.. it might be part of the agenda.. in some cases.. but not the primary.. reason for inviting a particular patient*

## 5.6.2 Legitimacy and representation

There was little data related to the legitimacy of patient research partners. However, the legitimacy of research partners was clearly based on first-hand experience of having a relevant condition, and no challenges to the legitimacy of research partners were expressed or observed. Researchers were clear that research partners were not expected to represent all patients.

*R4: we are asking you to come because you have experience that we don't have.. that's your individual experience and it will be very informative, we are not asking you to speak on behalf of all patients, and I think that is quite an important distinction*

Legitimacy of involvement was linked to diversity, the desirability of having a range of people involved with relevant and different experiences. However, while researchers in the rheumatology case study described involving people from different educational backgrounds, the group of research partner participants were white, middle class, well educated, and mainly older.

One researcher expressed caution about involving patients from patient support or campaigning groups, because they might want to pursue a political agenda, rather than focus on research with a willingness to consider different perspectives.

*R4: we never recruit patients because they represent a particular body.. so we wouldn't go to a patient society and say could you send us a representative to be on our ... project steering group, but there are systems in Europe where they do tend to do that.. it is possible that those patients bring a political agenda rather than a personal agenda and that's why we haven't done it really.*

Researchers valued experienced research partners' experiential knowledge (use of services was ongoing), and the experienced were also valued because they were likely to be comfortable in research meetings, familiar with terminology, and more confident. However, contributions from inexperienced research partners were also desirable. Pairing an experienced research partner with a newer partner was seen as a good model, allowing access to different perspectives. Experienced research partners were not seen as appropriate for all roles.

*R3: if I want a naive view of a questionnaire I don't think it's a good idea for me to ask somebody that we have been working with as a patient research partner for the last 10 years who has been to international conferences ... they don't have a naive approach to a questionnaire, and VAS means visual analogue scale to them and they don't even have to think twice about it.. but VAS to somebody else doesn't mean anything ...*

Experienced research partners also saw the benefit of new partners and different perspectives and one experienced partner did not want to contribute too often or be seen as providing 'the' patient voice.

## 5.7 Power

Researchers were the custodians of the technical and scientific quality of research and ‘in charge’, and there was no evidence that research partners wanted to control research, or wanted more decision making power. However, findings also reflected power being shared in research meetings, where working together was understood as a collaborative partnership. These perspectives on power in the case study both describe power relations.

*R3: part of the challenge of patient involvement in research is not to lose sight of the fact that the researchers are still in charge in the sense that the researchers have the expertise to know the direction you are trying to go in, and you cannot expect patients to have that*

*R5: they do feel part of a team ... you are working with them, there is a partnership going on*

In the broader context of research in rheumatology outside the department, the inclusion of patient perspectives was acknowledged to include struggles between professionals and patients. Researchers’ perspectives reflected the importance of technical expertise whoever initiated research, nor were patients always right. Senior researchers described how ideas suggested by patients needed to be tested out, they were not accepted uncritically.

*R4: we have four or five patient partners who ... wanted to develop a questionnaire on the web, and it has been really hard to persuade them that just as they are involved in our research and helping us drive it.. that if they start to move into the research area they need the equivalent of patient partners, so they need us.. because we have the research skills that they don’t have ... they weren’t getting that message ... [but] they need to apply the same principles to their research ... they need some professional help just like we need patient help*

*R3: we set out to find out whether what our patients had told us at [conference name] about fatigue was really true or not and it turns out that it was true, but we didn’t just take their word for it you see, we set out to find out whether it was true ... once we had found out it was true we realised we couldn’t ignore this, and then we have started a whole programme of work*

Within the department the two senior researchers saw patients as powerful allies supporting the department’s interests, again reflecting alignment of patient and professional interests, and this power was orchestrated by professionals.

*R4: we were fairly used to the power that they [patients] had so they would ... get things changed within the Trust.. by going to the Chief Exec. and saying this isn’t good enough, and made things happen, so we were quite well aware of their power*

While one research partner was willing to support the department’s partisan interests, another questioned whether patients should do so, because such support was not based on an assessment of what the hospitals’ priorities should be. This point of view draws on the

assumption that resources should be allocated between departments (and patients) based on need.

## **5.8 Conclusion**

This chapter has presented findings from the rheumatology case study. The next chapter presents findings from the domestic violence case study.

## **Chapter 6: Domestic violence case study**

### **6.1 Introduction**

This chapter presents analysis of data from the DV case study conducted in a university department where many of the researchers were based, and in two DV agencies. The university department was large and research there focused on a range of health topics.

The case study reports on involvement in an evaluation of the clinical and cost-effectiveness of a psychological intervention delivered by DV advocates to women experiencing DV. It was an individually randomised two-arm controlled trial conducted in two centres (DV agencies) in two cities. The trial was part of a group of research studies investigating different aspects of DV.

Over 250 women aged 16 years or older experiencing DV were recruited and randomly allocated to receive the 'usual' DV agency service support (control) or 'usual' DV agency service support plus the psychological intervention (intervention). Those in the intervention group received eight specialist sessions and two follow up sessions. Women in the control group received usual DV agency service support but no additional specialist sessions. Women taking part in the study filled in questionnaires when they were recruited and at 4, 8 and 12 month follow ups. The questionnaires measured violence, quality of life and mental health. The trial design was piloted in one centre; it ran at two centres from April 2011 and recruitment was completed in May 2013, follow up was completed in 2014.

The aim of the trial was to find out whether the psychological intervention was effective by measuring levels of psychological distress as a woman entered the DV agency compared with a year later. The trial investigated the cost-effectiveness of delivering the intervention in addition to usual DV services, and also explored both service user and DV advocate perceptions of the intervention.

The research team running the trial was large, some researchers were from other universities and one was a self-employed clinical psychologist. Some of the team had prior experience of public involvement in research. Involvement took place in two PPI groups, one based at each of the two DV agencies where the trial was conducted. The PPI group in the agency where the pilot was conducted (AG1) was formed in the planning phase of the trial in 2010; the PPI group in the second trial site (AG2) first met in October 2011.

Background information (D23 IRAS form) explained that DV services had a weak evidence base, access to services was problematic, and there was reluctance to commission services. While many women across the social spectrum were affected by DV, not all women sought help, nor did women necessarily know that services were available or how to access them. Some women who accessed DV services did so in a crisis, seeking safety in a refuge with their children; many women were trying to cope with personal trauma and there could be on-going problems of personal safety. Women might leave home without possessions, living in a refuge or safe house could be difficult, and it could take time to find either temporary or more permanent accommodation. If women returned to the perpetrator DV agencies did not usually keep in contact and DV was characterised by weak links between health services and DV services, where DV was often invisible to doctors and nurses resulting in poor quality health care (D23). Doing research with women in such circumstances was challenging.

Data were collected from March 2012 to April 2013 when the trial was recruiting participants and collecting data in follow up. I had no prior relationships with researchers or research partners in this case study.

Research team members who planned and attended PPI groups were the principal investigator, the research associates, the qualitative researcher and trial manager. Twelve research partners took part, six from each DV agency. Other researcher participants worked on the trial and attended the Trial Management Group (TMG); some participants (numbered 12-15 in Table 15) did not work on the trial but worked on other DV studies based in the department. The agency staff who participated attended TMG meetings. Within the department there were several other researchers working on DV studies, and another university department undertook research with some overlapping interests.

Demographic information was not collected from 13 participants who were only observed. The principal investigator was the only male participant. Out of eight research partners who provided background information only two had part-time or voluntary work, six had 'O' level or no qualifications, and five were white.



**Table 15: Participant descriptors in the domestic violence case study**

	<b>Name</b>	<b>Code in text and quotes</b>
1.	Principal investigator	R6
2.	Research associate	R7
3.	Research associate	R8
4.	Research associate	R9
5.	Qualitative researcher	R10
6.	Clinical psychologist	R11
7.	Trial manager	R12
8.	Researcher	R13
9.	Health economist	R14
10.	Statistician/Health economist	R15
11.	Researcher	R16
12.	Researcher DV group	R17
13.	Researcher DV group	R18
14.	Researcher DV group	R19
15.	Researcher DV group	R20
16.	Research partner AG1 <sup>1</sup>	RP7
17.	Research partner AG1	RP8
18.	Research partner AG1	RP9
19.	Research partner AG1	RP10
20.	Research partner AG1	RP11
21.	Research partner AG1	RP12
22.	Research partner AG2 <sup>2</sup>	RP13
23.	Research partner AG2	RP14
24.	Research partner AG2	RP15
25.	Research partner AG2	RP16
26.	Research partner AG2	RP17
27.	Research partner AG2	RP18
28.	Manager AG1	A1
29.	Staff member AG1	A2
30.	Staff member AG1	A3
31.	Staff member AG1	A4
32.	Manager AG2	A5
33.	Staff member AG2	A6
34.	Staff member AG2	A7
35.	Staff member AG2	A8

<sup>1</sup> AG1= DV third sector agency 1

<sup>2</sup> AG2= DV third sector agency 2

It was agreed that I would not collect data from agency staff delivering the trial intervention, from trial participants, or seek interviews with agency staff. See sections 4.4.1, 4.5 and Appendix 22 for more information about the characteristics of participants and data collection.

## **6.2 Involvement tasks and roles**

This section reports on involvement tasks alongside findings on involvement roles. In research funding and governance documents involvement was described as including consultation on

research design, oversight and management of the research and collaboration on interpretation and dissemination of findings.

*D23: We have brought public and health service user perspectives directly into the development of the [application], from the articulation of the research questions to the expectations of study participants to the plans for dissemination and implementation of the findings. The development of the [application] was directly informed by a consultation meeting with the [AG1] user advisory group, which includes 10 survivors of DV. [R6] presented the outline of [plans] to this group in July 2008; comments on the scope and design were incorporated into the next iteration. A user member of the [name] trial steering group, also commented on the scope and design of the programme.*

*D23: Members of our user advisory group will present our findings with members of the research team in these public and policy fora.*

The PPI section of the protocol (D27) emphasised the role of DV agencies as collaborators and involvement of the agencies' service user groups. The PPI section of the ethics application (D26) included description of nine qualitative interviews in the pilot phase of the trial, and seeking feedback from participants about the design of the trial and experiences of the intervention.

### **6.2.1 Involvement in design**

Researchers had consulted service users from AG1 when the trial was being planned in 2008, this was described in D23 (IRAS form), D26 (ethics application) and D27 (protocol); these documents also emphasised researcher links with DV agencies.

*D26: Service users, in particular survivors of abuse who are or have been clients of [AG1], have been involved as an advisory group in the design of the study (refer to Document 21). The PI and research associate will meet with this group or the service user group from [AG2], on a 6-monthly basis during the course of the study, seeking their input on management, analysis and dissemination. In the course of the pilot our research associate had extensive contact with participants and collected their comments on the trial design and intervention. In the course of the pilot our qualitative researcher interviewed nine participants specifically asking about the design of the study and the content of the intervention.*

Researchers initially consulted members of AG1's involvement group, and members of that group were then recruited to form the PPI group based at AG1. The principal investigator reported discussions about whether it was ethical and acceptable to randomise trial participants into intervention and control groups when little psychological support was available. Researchers were concerned that 50% of participants would get nothing extra, and discussions with research partners had included the possibility of offering two out of three participants the intervention. Researchers were unsure whether women would be willing to participate given this design.

*R6: there is a real dearth of psychological support for women who ... are surviving abuse, we are going to be recruiting them into a trial, but because it's a randomised controlled trial ... half of them need to get nothing ... what will women think about that?*

*R6: This didn't take a lot of discussion with the PPI ... group .. they said .. of course women will say yes because .. [it's] not just for them .. there is a chance that they will get help .. but they will do it for other women so we don't think you need to worry about that .. and don't worry about the 2 to 1*

Research partners were also consulted about follow up in the trial; DV agencies did not stay in touch with women who entered their services but later decided to return to a perpetrator of violence. However, researchers wanted to keep in touch with all trial participants for a year, and making contact with a participant who had returned to a perpetrator could raise concerns for their safety.

*R6: the agency will not retain contact with a woman if she has gone back to the perpetrator ... for a trialist that's a real problem ... but we took it to our PPI group and said what's your thoughts about us carrying on contacting a woman as long as we can do it safely*

As well as discussions about the design of the trial, research partners had considered the research priorities being addressed in a wider group of DV studies being planned.

*R6: we had a meeting where we said look .. these are the areas that we think .. we should be really focusing on ... what do you think of those priorities, are there others that you think we should be tackling? ... So it was advisory on the design actually at the proposal stage*

Other contributions were also reported including feedback on participant information documents. Two research associates also described early discussions with the PPI groups about how best to explain the research to potential participants and how best to approach them.

*Interview notes R7: For her personally they had helped her understand the situation of the women she might be talking to and how soon it might be OK to approach a woman and how best to communicate. She had had feedback on her approach and that was really helpful. [R7] had told them what she said in her pitch and they had given her some confidence that it came over OK and that they were supportive of communicating using the mobile phone.*

Because recruitment into the trial affected a woman's allocation to workers at the DV agencies (to staff delivering the intervention or not) potential participants had to be approached as soon as possible so as not to delay their access to support.

## 6.2.2 Involvement in the conduct of research

The main issues discussed in the PPI groups during my data collection period were recruitment and retention of participants. Recruitment of women was slower than anticipated and research partners contributed ideas for improvement. Specific issues discussed included whether researchers should follow up women who had agreed to meet them but failed to do so, and if they should, how many times. R7 and R8 were concerned not to pressurise women when they were vulnerable, but research partners felt that women were likely to forget appointments when other life issues were in the foreground, so they encouraged follow up and suggested ways to do it appropriately.

*RP8: I understand their [researchers] struggle and sometimes I feel bit guilty that I can't help them more with that ... women are ... willing to help but once they've moved on and started their new life or even some of them might actually be seeing their ex without anyone seeing ... they don't want to be involved.. so I do understand their struggle, I just ... there isn't a cure I don't think ..*

*R8: they've more given a stamp of approval to what we've been doing or said you know I don't think you can do any more, we don't have any more ideas*

At the March 2012 meeting in AG2 the PPI group considered whether it might be useful to direct participants to the trial's website for further information and to establish research credibility. Copies of some web pages were distributed for discussion. The researchers felt the website was not particularly accessible but research partners made positive comments about it.

As well as discussing recruitment problems researchers also discussed retention of participants in the trial at all PPI meetings. The aim was to keep 70% of participants in the trial for a year which meant completing research questionnaires at 4, 8 and 12 months. However, many participants moved homes and changed their phone numbers to be safe from perpetrators, sometimes several times, making follow up a challenge. Research partners confirmed that it was likely to be difficult to stay in touch.

6/3/12 PPI meeting AG1

*the women were not surprised that it was difficult to keep in touch with people in the trial or that it was also difficult to keep track of contact details*

Strategies developed by researchers included asking participants for alternative safe contacts, perhaps a mother or sister. Such strategies were discussed in PPI meetings and research partners reassured researchers that they were acceptable; they also suggested that researchers should use Facebook to stay in touch.

16/3/12 PPI meeting AG2

*RP13: Yea .. a lot of people keep in contact through Facebook*

*RP14: Especially for like the younger people ..*

*RP16: Because they are on it all the time ..*  
*RP14: With like under-fives...*  
*RP16: Yea and it's their life really Facebook ...*  
*R8: ... it seems to have taken over from emails*  
*RP16: ...most people have got their ... Facebook linked up to their mobiles.. so if you left a message you'd only have to put it on Facebook*

Contributions from PPI meetings were reported and discussed in the TMG where most decisions about the conduct of the trial were made. R8 followed up the idea about Facebook and it was discussed twice in TMG meetings; following the first discussion R8 sought further information about the use of Facebook in other studies.

8/5/12 TMG  
*R8: ... I did meet with ... one of the team members for the [study which uses Facebook] who deals with public engagement ... and the only way that you can use Facebook for this purpose .. which they do .. is to have a kind of generic page that people can 'like' ... you can't have people ... as friends of the trial because they can see who else .. is in the trial .. so we have kind of just had to decide .. that maybe that just didn't work*  
*A5: ... but if you have it as a closed group nobody outside the group can see what's .. there*  
*R8: but the group members can then see each other*

8/5/12 TMG  
*R6: ... we also ran it past our Data Monitoring Committee .. who ... are our independent group .. that have the final say around .. all things ethical .. and they were really very negative about it .. and really ... feeling that even a ... marginal risk of there being a breach of safety or breach of confidentiality made it unacceptable*

At the June PPI meeting in AG2 R8 explained to research partners why this suggestion would not be actioned and D32 (an update on the trial) provided written feedback. While research partners understood and supported the need to protect participants' safety, there was further discussion about whether or not it was possible to communicate with people confidentially on Facebook. Another retention strategy discussed was texting participants every month to remind them about the trial, research partners approved this idea, reminding researchers that participants were likely to forget about the research in the gap between questionnaires.

At the May 2012 TMG researchers decided to produce a leaflet to give to participants when they left the DV agency's service to remind them that they continued to be in the trial, in June it was suggested that the draft should be shown to the PPI groups, however, this was not followed up.

Incentives provided for trial participants to return follow up questionnaires were discussed at the November 2012 PPI meeting at AG1. £10 shopping vouchers were sent out with questionnaires (40 pages) with postage paid return envelopes. Research partners thought that

sending vouchers in advance was a poor strategy and that £10 was not enough of an incentive. Incentives for retention were discussed at the December 2012 TMG and notes of the November PPI meeting at AG1 were circulated to TMG members.

5/12/12 TMG

*R12: there was quite a strong feeling from a lot of people that actually £10 isn't really that much of an incentive .. to get the four and eight months .. questionnaires back ... and we thought well .. yes £20 would be more of an incentive for each one*

Discussion of recruitment and retention strategies gave research associates encouragement and reassurance about their processes for important research tasks. At PPI meetings research partners were given updates about progress on the trial and about other DV research, most were verbal, but in two meetings written updates were provided (D32 and D36). While D32 was referred to in the June PPI meeting at AG2, D36 was not referred to in the November meeting at AG1. At one PPI meeting there was discussion of potential research ideas.

### **6.2.3 Involvement on other research studies**

At three of four PPI meetings research partners contributed to two other DV studies being planned by R10.

*R10: the DV research group here is growing all the time and we've got more and more projects coming on line so I guess we are ... expanding the brief*

One study had already been designed and R10 described research plans at the March 2012 PPI meeting at AG1. R10 sought volunteers for pilot interviews and recruitment advice. At the June meeting at AG2 R10 sought feedback on a participant leaflet, recruitment advice and volunteers for pilot interviews.

Discussion of the information sheet identified research partner concerns about a clause on confidentiality which said that researchers had an obligation to report child protection issues to social services. Research partners felt that women would be fearful that children would be removed and be unclear what researchers might report. This feedback was discussed at the March 2012 TMG and the principal investigator noted that these insights were of general relevance for research in DV.

6/3/12 PPI meeting AG1

*RP8: I have noticed here you've got .. [reading from information sheet] the research team has a legal obligation ... you have to tell social services ... that's got to be a biggie why people don't want to do it ... that's why people might not want to take part in the study because of certain safeguarding issues*

*RP7: I think the whole problem is about social services ... it's like people think that they are going to come in and take your kids ... I mean I've never thought that but I know a lot of people that do think that ...*

*RP10: but some people don't know how severe things have to be for you to actually report it ... they have no idea .. so then they get very very guarded ... and they think oh if I say .. that I've shouted at my child then someone might [report it]*

*7/3/12 TMG*

*R6: the PPI group thought this was a really important issue .. and one that may undermine participation in research ... it also linked into the new study around integrating child safeguarding and domestic violence training ... so it was one of those .. but this often happens in the PPI group .. that it kind of takes off and then a whole new set of insights come out ... it was a really good example of that*

The design of a second study led by R10 was discussed at the June 2012 PPI group in AG2. The draft bid was sent out in advance (D34). Because this study involved participant data being made available to the public, different options for presentation of information and related safety issues for potential participants were discussed in detail. Research partners were supportive of this study and provided specific feedback on a number of issues.

Some research partners from the PPI groups also contributed to involvement on other DV studies being run in the department. This included one study which was initiated and funded as a result of research partners identifying a gap in research priorities. One researcher in the DV group had started another PPI group in a third DV agency, and another had identified and recruited research partners through existing contacts for a PhD study. Similar tasks were addressed in different groups.

*R17: We displayed everything we give to research participants. We also requested their advice on recruitment procedure and ... all these practicalities you know for instance how you should stay in contact with a woman, what is the best way to follow her without being too aggressive ... and then we had one session where we brain stormed ideas for the future research project*

#### **6.2.4 Involvement role**

The involvement role had included contributing to the design of the trial and review of study documentation. Researchers were aware that the length of the trial limited the role, once the design was agreed there was little scope for change, and recruitment and data collection went on for more than 3 years, so contributions were restricted to recruitment and retention issues for a long period.

*R8: we're confined with the design of [trial name] and the practicalities of ... having to see women quickly before their support starts, so there is a limit to what women can shape I think*

*R10: once you've got it funded you're a bit stuck with what you said you're going to do so it's going to be tweaking, tweaking the 'how' a little bit*

In the trial research partners were not involved in data analysis which was quantitative, nor were they involved in the analysis of qualitative data collected alongside the trial. However, D23 (IRAS form) described collaboration in the interpretation and dissemination of findings, which suggested they would contribute to how findings and analysis were reported. This phase was anticipated as an opportunity to develop the role.

*R8: I do think they will make a marked difference when they start talking about interpretation of results and dissemination.*

One researcher identified the need for involvement tasks to be clear without too much focus on providing information on study progress, with concern that research partners were actively involved.

*R8: I feel there could be more clarity on what is to be discussed ... what I don't want it to ... be is just a talking shop and there isn't any real core purpose ... I am aware of that and sometimes you know you put things on the agenda and you feel like there is an element of giving information rather than taking it back and [I am] mindful of it being a true opportunity to comment*

*R8: I think it's really important that we don't use them ... so they test out everything and that they're almost ... like a resource to be milked ... and that actually they're involved*

A need to address specific involvement tasks emphasised the importance of the timing of involvement meetings in relation to study activities. PPI meetings arranged for the trial may therefore have constrained involvement contributions to other studies.

There were Terms of Reference (D24) for the PPI groups in the trial which were produced during the design process, but these were not referred to at three of four meetings and one of the researchers organising involvement did not know they existed. They had been shared in AG1 early on, and they were discussed at the fourth meeting when the research partner role was reviewed. The purpose of the groups was described as:

*D24: to make sure the research is conducted informed by women who understand and have experienced domestic violence*

*R10: the first meeting I attended ... we actually took this along [D24] and that was one of the agenda items ... for the women ... and they all said yes its fine. But I'm never completely sure if they actually mean that or they're just sort of being polite and helpful*

When the Terms of Reference were reviewed in AG1 there was consensus that they were too formal, long and needed radical amendment. Following this discussion a new leaflet was drafted and discussed in the TMG (January 2013) but it had not been finalised by the end of my project.



*29/11/12 PPI meeting in AG1*

*R12: it's just not easy to read is it?*

*RP7: no ... and just one side of A4 would be better*

*R12: so is it a good idea for .. for us to kind of like try and redraft this and send it round for your input ... shall we do that?*

*RP7: Yea you could do that .. so you can do it again ... start it again.. start it again ..*

*[laughter behind] ... it's a dreadful thing to read really ..*

*A4: ... it looks like a contract .. it's awful ..*

*RP7: When I saw it I just thought no .. a bit is fine but no ... .. and it needs to be that size as well [A5 leaflet] ... .. that is something you are not going to read ..*

In AG2 the PPI group had an additional role; they also provided feedback on a range of issues relating to the agency's services. The agency did not have a separate service user group, and both meetings included time facilitated by agency staff. This was seen as a mutually beneficial arrangement for researchers and agency staff, with benefits for research partners who were paid more for their extended role. There were no shared involvement meetings with AG1 during my data collection period.

*R8: in [city] ... there was no group, no PPI group and so [AG2] as an organisation has seen this as an opportunity to access it as a ready formed group*

*7/8/12 TMG*

*[R8] said there may be child care costs involved which [AG2] would pick up. [R8] thought that the extra payment would make it more likely that the women would come along.*

A training day was held in March 2012 which was planned and delivered by researchers from another university department for research partners working on studies they conducted, but research partners from AG1 were invited and four attended. After the training feedback was sent to the principal investigator that research partners were not clear about their role or expectations linked to having dual role in research and service delivery. However, at the time the user involvement group at AG1 was not meeting, and it was research partners in AG2 (who did not attend the training) who had this dual role. I attended this training and my interpretation of the feedback was different.

*R6: some of the PPI members.. they don't really distinguish between advising [AG1] and advising the research... so that is something we need to try to clarify for them ... and .. I guess it probably means that [AG1] isn't convening that group independently which I hadn't realised*

*15/5/12: what I remember was one comment that it would be good to have written things ... before a meeting so they would have time to read them ... rather than giving off the cuff comments ... and another comment from [research partner] who said that she had come along some time before but that it was a while back and she could not remember when she came more recently what the research was all about.*

## ***Research partner role perceptions***

All four research partners interviewed described the role as straightforward, focused on sharing their views based on their experiences, without need for additional training or induction (see section 6.4.2).

*RP8: that's what they need us for, it's to speak up*

*RP7: it's just obvious .. you go in there, they are going to be sort of talking about what they are doing and they are ... leading the whole meeting aren't they, and asking questions and stuff, and then you ... just have to try your best to get involved*

Asking about the role met with some puzzlement; it was up to researchers to shape involvement to meet research needs and research partners trusted that relevant and important issues would be raised. Members of the PPI groups were approached to be participants in other DV studies, however, the difference between being a research participant and a research partner may not have been either obvious or significant. Two of the roles below are involvement, one is participation but no distinction between roles was made.

*RP17: I did the one [study] that we've been to and I've done the [name] project with [R10] and I've just done the [study on DV and children] project in [city].*

Motivation for taking part was improving services for women and children, see also section 6.3.2. below. A summary of feedback from research partners in response to a questionnaire designed by the trial manager (D72) confirmed this view.

D72: *What made you decide to be involved in this group?* 5 of 7 responses were:  
*To help other women in similar circumstances. To improve services. To do more about domestic violence. To increase knowledge and awareness of DV. To help researchers improve outcome for future victims.*

### **6.2.5 Development of involvement**

During my data collection period researchers in the case study reflected on their involvement processes and had a number of discussions about the development of involvement. This was prompted by a number of factors:

- Expansion of the DV research group and increase in number of studies in need of involvement.
- Limited researcher capacity for several months in 2012; one research associate (R7) was ill, so R8 had to cover both trial sites and there was no trial manager, therefore recruitment and retention were prioritised.
- In August 2012 a part-time trial manager started work. She had previous experience of involvement, and took on a leadership role.

- In the autumn of 2012 R9 took on the role of research associate for the trial, taking responsibility for recruitment, retention and involvement in AG1.
- My presence in the TMG was a reminder about involvement. Over time my relationships with researchers developed and I became a participant observer, and as a response to capacity problems helped more with involvement.

By October 2012 there was a perceived gap in involvement, and a need to reconnect with research partners in AG1 because there had been no contact since March 2012.

10/10/12 TMG

*R6: obviously the first part is to meet up with them again before they think that we have disappeared off the face of the earth..*

*R12: yes so we will make that a priority .. [R9] myself and Rosie ..*

At the November PPI meeting at AG1 feedback was sought from research partners on how the PPI group had been run and the involvement role. Feedback given at the training was reiterated, which included a request that documents for review were sent out in advance, and that meetings provide recaps about what the research was about.

Discussions about involvement in trial at the TMG identified that by early 2013 most recruitment and retention issues had been reviewed several times, with limited benefit of further input; but recruitment continued until May 2013 and retention until the summer of 2014. While researchers planned to involve the PPI groups in developing a dissemination strategy for service users and practitioners, findings from the trial would not be available until the autumn of 2014. Researchers felt that there would be more scope for involvement once the findings from the trial were available.

*R8: it will become more interesting when we start talking about findings and what it might mean, I'm really looking forward to that part and then looking at dissemination strategy and ...a meeting for survivors to make it approachable*

Researchers planned to explain the gap in involvement to research partners and identify what involvement roles might be available on other DV studies. This prompted the trial manager to develop a newsletter (D73 and D74) which was produced in the spring and summer of 2013 as a mechanism to keep in touch with all research partners, including those working on other studies.

In February 2013 plans for involvement were discussed at a meeting of DV researchers in the department which I was invited to attend. The trial manager circulated a discussion paper (D69) in advance with a draft leaflet to replace the Terms of Reference (D24). D69 included an introduction which identified involvement as '*almost mandatory*', having variable results and

costs that were often overlooked. The document asked what researchers wanted to achieve through involvement, suggested the need to identify sources of funding to resource it better, and identify who would take plans forward. A key issue was whether each study needed separate involvement arrangements, or whether the three existing PPI groups might be amalgamated. However, researchers were uncertain whether one group would meet all their different needs, and whether research partners from another city would travel to meetings.

Lack of capacity to support involvement consistently was identified as the most significant limitation to involvement because no staff had a specific PPI role; this had also been identified in TMG meetings.

*8/1/13 TMG*

*R12: so .. if [name] is setting up a new .. group ... then that's an example why .. with a wider group .. and if there was a co-ordinated effort in that .. then you wouldn't have to reproduce all of these things*

*R10: yes exactly .. and I think the problem is that there isn't any one person whose job it is to do that [involvement].. because if we were having .. regular meetings of a core group there wouldn't have been any need for [name] to have gone out there [to create a new group].. because there would a meeting on the agenda ... ..*

*R6: well I mean .. in the profile of the centre that we'd like to hopefully get funded .. I think you would want a full-time PPI post ... .. if you are serious .. about engaging*

The principal investigator suggested that some funding for research implementation linked to the trial might resource engagement and involvement work for a time, and researchers recognised the need for engagement with agencies and practitioners as well as service users for dissemination of research findings. This meeting did not make any decisions about involvement but agreed it needed further consideration.

## **6.3 Impact of involvement**

This section reports on the impact of involvement on research processes and on people, and includes the impact of my project on involvement.

### **6.3.1 Impact on research processes**

Researchers gave examples of the way that involvement had made a difference to the trial and other studies, but impact was clearer to some researchers than others. Research partners hoped that they made a difference but were unsure about their impact.

## ***Impacts reported during study design***

Research partner support legitimised applications in both the IRAS and ethics processes (D23, D26).

*D23: Survivors of DV, users of DV advocacy series and 2 organisations representing users are involved in the design of [name], will have oversight of the workstreams and will collaborate in interpretation and dissemination of findings.*

The principal investigator described two areas where the AG1 PPI group had contributed. Firstly, they had sanctioned the trial design, including randomisation of participants to the intervention and control groups equally. The principal investigator reflected:

*R6: ... I mean would we have done the trial without the PPI [support]?.. What if the PPI group had said ... you don't have a hope in hell of recruiting women to this because they are so desperate that they really won't want to get nothing .. and they will want to pursue their own [psychological support] ... I guess if that had been a strong message maybe we would have abandoned the trial ... and ... if they had been right we would have not had a successful trial ... as it is we are having challenges about recruitment but I don't think it's around those issues ... you could say they had the power.. to say don't do that do something else ... or they could have said yea do the two to one .... I mean in a sense there were no further mediators ... if they had said don't do the trial .. we wouldn't have done the trial .. if they had said .. use a two to one ratio we would have .. done the two to one ratio*

Secondly, research partners had endorsed the follow up of women in the trial even if they had returned to a perpetrator, which was not DV agency policy. The principal investigator acknowledged that from a researchers perspective such follow up was very important, and the procedure changed between the pilot and the trial.

*R6: so they gave us the.. moral.. not authority.. but approval that we could pursue this issue and in the trial we are, so if a woman drops out of the service we are still.. [following up] we didn't do that in the pilot which was problematic.. so now we are doing it and I am not saying that PPI input there made all the difference ... but they gave some.. a bit of courage.. to say to the agency ... we need to go beyond your policy.. so that is another example of [how] getting the PPI approval ... helped us*

Researchers reported that research partner contributions had significantly improved study documentation.

*Interview notes R7: said that they had really improved the study documents, before they had been too complicated and too long.*

Three different draft versions of a recruitment leaflet to be given to potential participants by agency staff were discussed and improvements were reported in the wording, artwork and balance between simplicity and information provision.

*R10: she'd [trial manager] actually prepared three versions of a leaflet and we took all three along and I thought that was really constructive .. because we were ... looking at things like, you know artwork to put on it, and phrasing of it, and I felt that was a really useful piece of work because this is the first thing that the women receive ... to take home and read so we had to get the balance between giving enough information but not over-burdening so as a result of that we did actually design that leaflet based very directly on the women's feedback*

*R6: they have helped us with designing a leaflet for recruitment.. which is better .. I mean vastly better than what we had before*

However, one researcher felt that requirements of ethics committees constrained how much researchers could change study documents in response to research partner suggestions.

*R10: I do think there's a limitation to what you can do in a way because ... in the information sheets that we provide [content] is very directed by the requirements of ethics*

### ***Impacts during conduct of research***

The research associates reported valuing feedback about how best to explain the research to potential participants; however, no specific changes to the approach were reported. Some recruitment procedures were modified as a result of involvement, for example, women were not approached until they had been admitted to a refuge.

*R8: we talked about the points of recruitment and how, how women would be feeling when they were asked about the trial and the practicalities of saying yes at that point in their lives.. and so based on that ... refuge women were being asked about the trial when they first came in to [AG2's] service .. that could have been just in their pyjamas as they'd left.. immediately. So they were being asked there and we stopped that point of asking and we brought it into the refuge*

*R8: In terms of what's come out of [AG2] then they've refined some of the process issues for us*

Discussion with research partners supported changes to incentives for trial participants to return questionnaires. Voucher value was increased to £20 which was not sent until questionnaires were returned. Research partners reviewed and endorsed modifications to recruitment and retention processes proposed by researchers, including follow up procedures and use of the trial's website, and making contact with trial participants through trusted family members.

5/12/12 TMG

*They were talking about giving participants £20 for the final questionnaire, and R8 said that it made a real difference – 'it's worth the woman doing it for that'.*

### ***Impacts beyond the trial***

One direct impact from involvement in the research design process was that studies on the impact of DV on children were prioritised.

*RP6: as a direct result of them saying 'where are the children?' we have now got .. a new grant that's been funded*

*RP6: we are putting in another grant proposal ... which is related ... [about] how you might intervene in a cycle of violence so that children who are exposed to abuse at home.. when they become adults don't themselves become perpetrators or victims ... and that came directly out of ... one of the members of the group saying.. 'children?'*

One study had been funded to investigate GPs' response to children exposed to DV, and a second research application was also successful. The principal investigator described this as evidence that things could get missed out if only researchers identified research priorities, however a research partner felt this was an obvious priority.

*RP7: that's come out of what we said then but it's pretty obvious stuff ... I think it is but maybe for a researcher it's not*

Impacts were also reported on other studies, including changes to study documentation, and modifications of a questionnaire based on research partner feedback. The impact of contributions by research partners on other studies was not directly investigated because this was outside the scope of my project.

*RP10: I've actually taken that line out as a result of what the women said ... so that was a change that I did make as a result*

*RP20: So we've changed the questionnaire to put in additions from them and we have also taken their advice on patchiness in service provision.*

*RP17: I definitely learn from them ... right now I'm writing a research bid for funding and I think that I use language which is ... simpler and easier to understand*

The PPI groups were a resource for a range of studies and outcomes of involvement did not conform to study boundaries.

### **6.3.2 Impact on research partners and researchers**

All four research partners interviewed were positive about their experiences of involvement; feeling that they were helping other women was a source of satisfaction, and they enjoyed meeting other women with similar experiences.

*RP7: It does make you feel like you are helping ... society ... because you could just be sat on the sofa but you are not, you are helping towards something*

*RP8: it's like a relief in a way that this is being discussed and they are thinking about how it can improve for the future, so it is a positive thing ... that's how I feel, it's very positive and hopeful*

*RP16: it's helpful to hear other people's stories and also to feel as though you are contributing towards helping other people as well because that does make you feel quite good really.*

*RP17: I like doing their projects, I enjoy them, I look forward to the next one ... cause it's something that's mine ... I've always got my home where I'm Mum .. and I look after my son and I'm with my partner and stuff, but that's something that's mine and I like having that.*

It was important for research partners that research was focused on benefits for women and children, and on improving services. Having originated a study on children one said:

*RP8: It's fantastic that they're going to look into it and do it .. so I'll support the researchers wherever I can ... because it means a lot to me ... it gives me hope for the future that children won't have to hang themselves*

Several research partners said experiences in the PPI group of being listened to, appreciated and valued were important because this was different from experiences of DV, and helped to increase self-esteem and confidence; one reflected that researchers taking notes increased her sense that suggestions were being taken seriously.

*RP7: it's like a relaxed atmosphere, you feel like you are appreciated, you feel like your opinion matters ... and maybe when you have been in an abusive situation you don't feel like [that] ... you feel the opposite, you are not valued you are not listened to ... and I think women might get strength from that, cause they might think hang on a minute actually .. I am like worthy .. and I can help ... I am doing this on my own and ... I am doing good .. for something so it gives .. it can give people confidence*

*RP17: well they always say like .. if you say something and they think oh that helps us, they always tell you, thanks for that and they'll write it down and they'll say who said it and stuff ... they'll take notes.*

Feedback on involvement given in D72 from 6 research partners identified that they had gained confidence, felt valued and empowered, alongside gaining increased knowledge and awareness of DV.

Some research partners described being nervous about their role at first, but it was easy to contribute to meetings and after encouraging experiences this changed to positive anticipation. Two commented that the groups were places they were listened to, felt comfortable, could be themselves and feel accepted.

*RP17: when I first started going there [AG2] ... I wasn't a very talkative person, very quiet ... but ... [now] I look forward to going there. I was very nervous to start with .. but [now] I look forward to it and I'll always ask when the next meeting is and I do*



*enjoy going in .. you sit there and ... you have a giggle and have a chat with the others and we are very open with each other ... I feel comfortable when I'm there, really comfortable, and I can just be who I am*

19/6/12 PPI meeting AG2.

*Right at the end of the PPI meeting today [RP16] said ... that this was a place where she could be herself ... that it was a really nice thing coming to the group.*

Feedback from a new research partner was given at a TMG.

5/12/12 TMG

*R12: the feedback .. from being involved in that PPI session .. was that nobody had ever really listened to her before .. or listened to her point of view and she just thought it was a really welcoming group .. and actually a really nice atmosphere*

RP17 had moved on from when she entered services, at that point she was nervous and withdrawn and did not want to engage in activities, but once she was established in her own home she appreciated meeting other women with similar experiences and getting involved was felt to be her own activity (see above), drawing on her personal experiences, and increasing her confidence.

*RP17: I'm grateful for the group because I didn't do any of the.. when you go into refuge you get a lot of projects and things like that.. I didn't do anything like that, I just kept myself to myself when I was in refuge, I didn't speak to anyone really and I think these [PPI] groups have helped me with my confidence and helped me ... enjoy things more.*

The informal conversations over lunch where experiences were shared were appreciated alongside the opportunity to contribute to the trial.

Although some difficult feelings were expressed in PPI meetings and during lunch breaks, they did not appear too significant in that the women continued to interact and contribute without apparent distress. However, in interviews two of the more experienced research partners commented that involvement could revive difficult memories, but that this did not put them off being involved. One felt this was inevitable, and not only in PPI groups, and while this might lead to flash-backs it was something that had to be dealt with and was part of the healing process. Such negative impacts were seen as unavoidable given experiences of abuse, data on this issue and the implications for support is presented in section 6.4.1 below.

Most researchers involved in the PPI meetings felt that contact with research partners was a valuable connection with service user experiences and perspectives, and two reported feeling motivated and enriched. One was pleased that she was able to create a friendly atmosphere and that women had decided to swap telephone numbers.

Interview note: [R7] said that all the women had had an impact on her personally ... she saw them as brave and had real respect for them. She said that it was good to see that some of the women made progress and got into a better place over time.

R8: ... the achievement that I felt was bringing women together who then found some kind of ground and they swapped numbers independent of any suggestion of mine ... that I'd actually provided a warm enough environment that that felt okay to do

R8: for me feeling you know as a recruiter, feeling more connected and understanding the process from the service user's point of view

R8: ... it felt positive. I felt uplifted at the end of it

R17: And it's [doing research] up and downs, never ending ... and sometimes I do not feel great ... and they just help me to cope ... for some reason every time ... when we meet I'll discuss this and that and I leave meetings quite re-boosted, empowered.

The role of R7 and R8 on the trial was to support recruitment and retention, and liaise with the DV agencies with limited connection to participants' experiences of violence which they valued in involvement. However, R10 felt more distant and did not feel any personal impact. In addition to an involvement role she was conducting qualitative interviews with trial participants, and felt that involvement did not have any additional or distinct impact.

R10: I just feel slightly separate so I don't feel any personal impact really.

### **6.3.3 Limitations to impact**

The principal investigator described some important impacts of involvement from his perspective, but he also recognised that research partners may not know what difference they made.

R6: the stuff that comes out is important.. even though I don't think the PPI group necessarily realises it .. so we have to find a way of .. of affirming that, somehow acknowledging it more.. in a better way

Uncertainty about impact was confirmed by research partners; at the start of my project the research partners in AG1 did not realise that two studies had been designed and funded as a result of their input. Although research partners felt appreciated they were unsure what difference they had made.

RP17: when they ask me things ... I try and help as much as can ... so I hope that whatever I say does help them.

RP8: I don't know I.. I don't know ... that I don't know I'm just waiting for the outcome and then to see ... if there's the end result. I can't wait to get there

Some researchers were also unsure about the impact of involvement although they felt it was important in principle.

*R8: I don't think it's made such a huge difference [to recruitment and retention processes]*

*R10: I don't know how useful they are in terms of dealing with specific issues ... I don't know, now you're questioning me, I just think.... how useful are they? I feel it's a good principle that we are engaging with users ... but I think we are also constrained about how much we can do something*

Impact was linked to having involvement sufficiently early in the design of studies, and one researcher regretted that there was no involvement in the TMG.

*R8: so I think it's really important that... if they are to comment on the projects we're not bringing it for them to rubber stamp, we actually are bringing it at the right time so they can comment early enough so that something could happen based on the feedback*

*R10: Well that's where my new projects come in ... where I'm actually now writing the grant application .. I think there is room for substantial input there*

*R11: I think sometimes ... what I've missed in [trial] compared to [prior study] is having somebody on the steering group. There is something different about having the presence of an expert by experience in the room, not least if it's just a small thing to be able to turn to them and say 'what do you think'*

More significant impacts reported resulted from involvement in the early stages of research, during the design of the trial, than were reported on the conduct of the trial. Improvements to study documents were the most concrete improvements reported at this stage. Impact on recruitment and retention was limited to review and endorsement of strategies, and some suggestions could not be adopted. More scope for involvement was anticipated in interpretation of findings and dissemination.

#### **6.3.4 Impact of my project**

At the beginning of my project I did not know any of the participants in this case study, and my initial stance was not to participate in involvement or research meetings. However, at the TMG I needed to complete the consent process at the start of the first meeting I attended to collect data. Over my data collection period I often needed to recruit additional participants who were attending TMG meetings; recruitment processes therefore drew attention to me and my project in the TMG. At the first two PPI meetings my project was also the first item of the agenda, because I needed to recap on why I was there and complete the consent process. At both subsequent PPI meetings I needed to explain my study to research partners who had not attended previous meetings and seek their consent. Therefore my presence was in the foreground at the start of all involvement meetings.

At the April 2012 TMG during a discussion about support for research partners I was invited to contribute based on my involvement experience. From this time onwards I occasionally

contributed to the TMG. In the summer of 2012, when research team capacity was lowest I helped researchers to support involvement as I was already attending PPI meetings. I did not organise meetings or contact research partners. Over time I developed relationships with project participants and my contributions to involvement discussions increased. In November 2012 at AG1 I drafted the agenda for the meeting and facilitated one item of the agenda reflecting on the involvement role.

Conducting a project on involvement which included attending meetings regularly inevitably raised awareness of the topic, with the potential to change practice and/or provoke feelings, potentially including anxiety. Some researchers sought informal feedback from me about involvement activities. Some of my experiences in the TMG were ambiguous; for example, one researcher was teased when she made comments about her commitment to involvement, and when she protested there was laughter about her being a 'believer'. My interpretation was that the laughter related to a potential gap between rhetoric and realities in relation to involvement, amplified by my presence.

At the last TMG I attended in April 2013 I asked about my impact on involvement.

*Rosie: and me being here and my focus has probably changed something ...  
R11: it was one the first things that I thought about when I sat down thinking we were saying goodbye to you .. that there's a sort of a Hawthorne effect .. about you being here.. I think is a little voice of conscience [background mms] .. and.. I think that's quite hard to quantify ...  
R6: I think that's right ... I mean I was always acutely aware when .. as today .. PPI seems to keep on falling off the agenda and I think .. oh! .. and Rosie's here [laughter general] .. and why .. dammit I don't know .. I mean the qualitative [work] does as well .. so ... I think you have been more than an observer .. you have been a participant observer ... and you have made a conscious offering of support to us ... so I think you have really influenced the shape of what we have done .. [mms] in relation to PPI .. you know the voice of conscience ... but also helping us with some really good strategic ideas .. about how to engage*

At this meeting the trial manager also thanked me for my contributions to involvement, and said that my presence had made a difference. I was given positive feedback about how I had conducted the project, and agreed that I would circulate my draft case study to researchers. I offered to go to a DV group meeting and/or provide feedback to research partners when I had finished the project.

Becoming a participant observer and more of an insider demanded careful management of confidentiality between participants. I had to negotiate what I shared in the TMG; for example I gave feedback about a research partner's anxiety but only after explicit discussion with her. My perception of feedback given by research partners at the training day was different from

the feedback given to the research team, but it was given by a researcher who was not a project participant so I could not use this data directly, even though she knew that feedback had been shared with me.

## **6.4 Processes, mechanisms and resources**

Researchers and research partners worked together in PPI groups, one in each agency where the trial was conducted. Four meetings took place during my project, two at each agency. Research partners only contributed in PPI meetings.

Researchers had friendly relationships with research partners but there was not much contact between meetings. In AG2 R8 was the main contact for research partners throughout my data collection period, but the researcher liaising with AG1 changed so research partners in this group did not have ongoing links to a known researcher.

*R8: I have contacts around trying to set up the next meetings but no ... I don't have an on-going phone relationship or anything*

### **6.4.1 Important involvement processes**

This section presents findings on involvement processes.

#### ***Organisation and facilitation of meetings***

Research associates organised involvement; arrangements for meetings required researcher liaison with agency staff to find suitable rooms, making bookings, and sorting out catering. Research associates evolved their own systems for keeping research partner contact details, when R7 was ill this made it difficult to identify and contact members of the group. Creating a circulation list for the newsletter took the trial manager time because it was difficult to identify all the research partners involved, and agency staff were not aware which of their service users or ex-users were involved in PPI groups.

At three of four involvement meetings agendas were provided. R8 provided agendas at both PPI meetings in AG2 (D28 and D31). D31 provided introductory explanations to issues for discussion. Documents for review and comment were only sent out in advance for one meeting (D32, D33). After one PPI meeting notes were produced (D37).

PPI meetings were welcoming, friendly and informal, and researchers stressed the importance of this approach. Hospitality included provision of drinks and snacks, lunch and space for research partners to catch up informally. Most research partners appreciated this time to informally share experiences.

*Interview note: R7 felt it was important to stick with what they were comfortable with and their ways of doing things, not to impose more formal systems.*

*R10: over lunch.. they're all chatting to each other about their experiences and their children and one thing and another*

*RP17: it's a really friendly atmosphere because obviously you get all the different women with their different stories and you've all been through the same thing ... you go there knowing ... although it's not very nice, you have something in common with the other people there*

At least two researchers attended every involvement meeting; more researchers attended meetings in AG1 because they were held in the same city as the department. One researcher took an overall lead at each meeting, but agenda items were led by different researchers. Having more than one researcher present supported good facilitation, researchers asked each other questions to clarify information and encouraged quieter research partners to contribute. Facilitation of these meetings appeared straightforward and contributions flowed once agenda items were introduced; research partners often asked questions and discussions were lively.

However, researchers noted that research partners had a tendency to be polite and positive, and needed encouragement to be critical. At the June PPI meeting at AG2 R10 explicitly suggested that research partners were critical of some draft documents, and R8 encouraged a focus on women who might not be so positive about research when giving feedback.

*R6: on the whole .. people who get involved in PPI activities are polite and ... they don't want to offend you.. partly that is a power relationship.. and partly it's just I think people's natural politeness, particularly in England I would say .. so you have to get past the politeness ... to help the PPI members get over their own desire to say ... this is good ... the thing with the PPI is saying actually we do want to hear the bits that you think that we are getting wrong ... so helping people say negative things I guess is what I would say you need to do*

*19/6/12 PPI meeting AG2*

*RP18: It does look user friendly ... as you say .. colour helps ... well I've tried but I can't find anything wrong with it (laughter)*

Less helpful facilitation strategies observed were not sending out documents for comment or review in advance, and this was also noted by research partners; providing too much introductory verbal explanation when seeking feedback on documents; and when discussing potential use of the trial's website questions were quite general, so it was difficult for research partners to make specific suggestions for improvement.

Researchers described the PPI groups as observing 'normal rules' about confidentiality, but there were no reminders about confidentiality or other ground rules at the meetings.

However, in DV services confidentiality and safety were emphasised, so in this context such agreements may be taken for granted.

Most communication with research partners was by text or mobile phone, while some had emails this was not the usual method of communication. Two research partners did proactively contact researchers between meetings to my knowledge and researchers felt they encouraged contact, but one research partner who was anxious about lack of contact did not feel able to get in touch.

*R10: they know our e-mails and they know our phone numbers and they are always invited to get in touch if they have got any queries or issues*

*RP16: I wouldn't like to text [researcher names] to ask how things are going or whatever .. because they might think 'you have got a bit of a sticky beak'*

*I: ...what does that mean, I have never heard that phrase before ...*

*RP16: ...sticks in something yeah, sticks in where it's not wanted*

Contributions made in PPI meetings were routinely reviewed in the TMG, there was feedback and discussion of involvement at every TMG that followed a PPI meeting. Of 15 agendas for TMG meetings seven had PPI on the agenda; of 15 sets of TMG minutes six had a heading and content for PPI and another five had some reference to PPI. Some discussions about involvement were not reported in minutes. Although involvement was not discussed at all meetings there was significant time spent on involvement in the TMG.

### ***Need for recaps and feedback***

In AG1 there was an eight month gap between PPI meetings, and in AG2 there were no PPI meetings between June 2012 and April 2013 when my data collection period ended, this meant research partners needed reminders about the aims and conduct of the trial. Not all research partners attended every meeting, so gaps for some individuals were longer.

*14/3/12: this comment did not seem to be about [role] confusion ... but just about ... needing a bit of a refresher after a gap.*

R8 and R10 gave feedback about suggestions made at earlier meetings, for example the use of Facebook for retention, and provided updates about study progress which was important for research partners. Two research partners interviewed would have liked updates about other DV studies being run in the department.

*R10: in a way feeding back as well we are saying that we value you ... of course the other thing that I haven't mentioned is that we take preliminary findings to them, you know it's a two-way thing, we're not just asking for information. We say look what we're finding is this and when we've got results, we will take them to the PPI group and let them know what the end product is, and I think that's real important as well*

*28/11/12 PPI meeting at AG1*

*A3: I think one of the most important things that has been said this afternoon was the feedback that you gave regarding the comments that were made ... and that actually that is something that is going to be going forward ... rather than .. you give this information and you never hear anything back about it again ... that was the most powerful thing that's been said*

*RP7: you can't just think 'oh a man that hits a woman is just a monster and that's the end of it'.. they need help, they obviously have got serious issues ... I think that was interesting that [R6] was like looking into all that and I haven't really heard any more about it*

Some written updates were given; a trial update prepared by R8 for the June AG2 meeting (D32) was accessible and included feedback from the previous meeting.

D32: What we're thinking about Facebook

- If we are friends with people on Facebook then people will be able to see who else is in the trial, which means that participation would no longer be confidential.
- Worries about confidentiality mean that we are unable to take this forward.

In the spring of 2013 the trial manager initiated a newsletter (D73) for research partners as a mechanism to keep in touch and provide feedback in a period when PPI meetings were less frequent; the second one sent out in the summer (D74) included a short piece written by me thanking everyone for help with my project. The newsletter provided feedback on all DV research studies being conducted, and was shared with all research partners involved in studies in the department.

### ***Support***

Researchers had two discussions about research partner support in the TMG. However, researchers who attended PPI meetings did not describe a significant support role and nor did I observe any lasting distress at meetings; research partners appeared to manage personal disclosure in ways that were comfortable. Nonetheless, researchers gave some examples of distress at other PPI meetings, and were aware that experiences of DV could be recent or ongoing.

*R8: I had a couple of women who felt really teary ... but I suppose that's par for the course.. it was a woman.. the experience was fairly recent and to some extent on-going*

*R8: we have had one woman ... from the first group ... [who] returned to the perpetrator and I did a welfare check to the agency because I was so worried about the way that she sounded on the phone ... but there's a limit ... I can't advise her.*

Researchers were aware that sharing experiences could trigger memories of abuse and distress, and this was confirmed by research partners.



*R11: one of the things that ... we're increasingly aware [of] is that even though women have accessed services, even excellent services like [AG1], they often have not talked about their experiences of abuse in detail, or indeed the psychological effects, and when they do they can be triggered to remember the incidents or the abuse or some of the problems they had earlier on ... for instance, when we were asking women about our difficulties in recruitment and why people might not be choosing to join the trial the PPI group were given us feedback like, 'oh well it's so difficult at that stage, everything's in chaos; there's so much to talk about and sort out' and 'women will still be shocked' ... that isn't a million miles away from them recalling and/or reliving their own experience and ... we hope that they are either sufficiently removed from it or sufficiently recovered that that isn't going to be difficult or upsetting, but it is an ask*

*RP7: we were talking about ... how kids are affected and I started crying because obviously my son had to be moved.. like moved schools quite a bit and ... .. and I started crying and I think everyone in the room was sympathetic but ... I've then got to walk out into the street ... feeling like that ... I might not have any support, I can ring my mum so I am ok, but other people .. they might not have anyone to ring*

*RP8: Sometimes it might bring back a memory but that is going to happen, that is going to happen for maybe years to come, it is part of the process, it's part of what's happened, so if it does it does. Something I might have put at the back of my mind might now be at the front of my mind.. but that is something I know I've got to deal with ...you know maybe next week I'll have a flash-back it is part of it, and it's part of healing as well ...*

Two of the research partners interviewed felt that researchers had some responsibility to respond to distress, for example by telephoning the research partner later, or asking a DV agency support worker to do this, but they did not feel that it was the researchers' job to provide on-going support. One suggested that it might be helpful to remind women that they did not have to share their experiences.

*RP7: the people who are doing the study need to ring the support worker and say look I am a bit worried [name] has just left here crying ...we didn't mean to upset her ... we were just talking about blah, blah, blah .. could you give her a ring ... .. so actually some thought about that ... afterwards ... .. [and] I think it's got to be made clear that if you don't want to talk about it you don't have to ...*

Having part of the meeting at AG2 focused on the agency's services seemed to increase disclosure with potential for distress, because members reflected on their experiences when using services, however this did not appear to stir up unmanageable feelings.

*19/6/12 PPI meeting AG2*

*Perhaps this led to more disclosure at lunch when there was quite a lot of personal discussion about histories and backgrounds ...my sense of it was that it was quite therapeutic or at least supportive in a way – it was not that heavy but some feelings were clearly stirred up. All of the women spoke about their situations to some extent. But the feel in the room was fine.*

At the TMG in April and May 2012 there were discussions about support following consideration of research partners being recruited as research participants, where interviews

would seek significant personal disclosure. Researchers felt that this was different from PPI meetings where research partners could choose how much they disclosed and experiences were not described in detail. This led to discussion of participant support needs in a range of studies.

*12/4/12 TMG*

*R11: I think it's very different for somebody to sit in the PPI group and comment as an observer about the process .. and although they will use their own experience about that .. it's quite different to be the focus of attention*

*R10: yea I agree*

*12/4/12 TMG*

*R10: it is an interesting point .. because when I look back at other projects I have worked on .. which have been in mental health ...where I have interviewed people attending at GP surgeries for mental health issues ... there has never been .. any support in place .. this makes me reflect on how projects are set up and we are interviewing people randomly from a setting and what responsibility I have ... that has just been simply if someone's distressed to say go and see your GP*

Researchers and agency staff were clear they shared a duty of care for research partners, but agency staff were not necessarily aware who was active in the PPI groups. Therefore, researchers and agency staff identified a need to clarify who would provide support, of what kind, to whom, and how it would be accessed. The duty of care described included providing a safe space for meetings and information about sources of support if it was needed. Potential support mechanisms for research partners were discussed, and the DV agencies were seen as the obvious source of support.

*R11: the possibility to either de-brief or be able to have support if people remember painful things about their past or find it difficult I think is really important.*

*8/5/12 TMG*

*A1: I think they should be anchored with us ... we have got enough of the responsibility .. we have got them into this ... .. we should have some ownership ...*

There was agreement that the researchers' role was to provide initial support, at or after PPI meetings, and to signpost to further support. This discussion identified a number of quite complex issues to consider, including that some research partners were no longer using agency services, and how research partners could access support without contacting researchers. R7 was asked to follow up by drafting a support plan which would be discussed with the agencies and research partners. However, she became unwell and no further action was taken.

In March 2013 I discussed research partner support with the trial manager, who pointed out that researchers supporting PPI meetings were unlikely to know the personal histories of research partners, or whether DV was a current or past issue. Support needs for researchers,

as well as research partners, was being discussed in the wider research group. During my project some researchers disclosed personal experience of DV to me and others noted the impact of accounts of violence.

*R12: one of the things we're exploring ... is this whole issue of vulnerability .. of vicarious trauma in staff ... in the research associates who are listening to stories ... and staff that work within that environment ... and how to address that.*

#### **6.4.2 Involvement mechanisms**

Organising involvement in PPI meetings had both benefits and constraints. Meetings were not frequent and some involvement issues discussed at the TMG were not followed up; this included getting feedback on a leaflet, and agreeing support mechanisms - see sections 6.2.2 and 6.4.1 above. However, lack of follow up was also due to researcher capacity problems, and there was some flexibility about dates of meetings.

*R10: ... I didn't want to wait for the next one [PPI group] because of the date of when I have to submit my grant application so I have set up a separate meeting, an additional meeting in June, specifically to run this new project past them*

The first two meetings were both held in March 2012 but some agenda items differed. In June 2012 a PPI meeting planned at AG1 was cancelled while one was conducted in AG2. In November 2012 only one PPI meeting was planned at AG1. The timing and organisation of meetings meant that some research partners contributed on some issues but not on others. Breaks between meetings were long, partly related to the length of the recruitment and retention period for the trial. Running two groups required more staff time to arrange and facilitate, and significant time was also required to consider contributions in the TMG.

Having two groups in two agencies involved more research partners with a range of experiences who had used DV services in both cities where the trial was conducted. In AG2 research partners outnumbered researchers at both meetings, and while more researchers wanted to attend PPI meetings in AG1, they tried not outnumber research partners. In this way holding PPI meetings provided a strong research partner voice in relation to researchers. Conducting meetings in DV agencies was also on familiar territory for research partners, not the researchers' home turf. The meetings allocated significant time to service user perspectives in a systematic way, supported accessibility, enabled researchers to hear views from a number of research partners, and allowed research partners to discuss issues between them. Nonetheless, researchers set the agenda and research partners were only asked about specific issues without exposure to research team meetings, with less opportunity to learn about and understand the wider research process. However, research partners were asked about research priorities and time was allowed to discuss issues that emerged at meetings, so

meetings did facilitate some unexpected contributions. There were no formally agreed policies or procedures for involvement in the DV research group or in the wider department.

### ***Learning and development***

As described in section 6.2.4 research partners found their role straightforward and did not feel either induction or training was needed, and one was surprised at the suggestion when the role was obvious. Within the structure of PPI meetings it was fairly obvious what was required, and even if RPs had been nervous about their role this did not last (see section 6.3.2).

*RP17: I didn't know who was going to be there or what I was going to be asked [at the first meeting] ... but no .. the way it was done was fine ... I didn't think any sort of induction or training was needed*

*RP7: No I don't think I need it [training] ... what to help with research?*

*I: yea*

*RP7: .. I don't think I do*

A training day was offered to research partners from AG1. It was organised by researchers in another university department. The day was attended by four research partners from the other department and four from AG1. The training was adapted from research methods teaching for students, and there were a number of presentations on different aspects of research, followed by a discussion of involvement experiences. Both research partners from AG1 who I interviewed attended this training day, and neither had found it particularly useful, because they felt it was geared to people who were going to conduct research, and not to their role.

*RP8: I think for us personally it didn't do a lot ... it explained the research but it didn't explain how me and [RP7] could help the researchers more .. and that's what we wanted*

*RP7: ... it felt like I was in a classroom with people that might be trainee researchers ... I really just didn't know what was going on*

The trial manager felt that training for research partners could be useful but not all researchers felt that training was necessary.

*R12: I think we should offer training but I think we need to work with the PPI people as to what that might be. And it might be different for different people as well.*

*R10: I just don't particularly feel they need training ... because to me the ... value is .. themselves and their unsullied experience if you like. So they can speak from the heart.*

## **Researcher skills**

Most of the researchers supporting involvement were not health professionals. The research associates responsible for organising involvement meetings took a practical and pragmatic view of their role; they had no prior experience or training. R7 and R8 expressed some anxiety about the work.

7/6/12 TMG

R8: *I have to say I do the agenda .. rock up .. do a good lunch .. try and be nice .. .... I know that's not very adequate ..*

*Interview note: I asked [R7] about her support for taking up this role and any preparation. She said she had had no formal training – she said she did not ask other colleagues about how to 'use' the group or about different formats, and she did not have anything to compare it to ... and wasn't sure what to do for the best.*

However, some generic research skills, in particular qualitative research skills like interviewing and running focus groups, were seen as transferable to involvement. While most researchers felt that they had the necessary skills to facilitate involvement, two expressed interest in further training. One felt that sharing involvement experiences across studies would be of significant benefit. In a discussion about research partner support needs in the TMG R11 acknowledged that they had not addressed how researchers might cope with emotions or difficult group dynamics.

*R10: well I do actually think it's quite good having a qualitative person in there ... I'm always engaging with users and I think that actually is quite useful ... you just have those skills really.*

*R19: ... investigating what are other people doing .... let's have a look at service user involvement in your study ... so what does that look like ... how are you managing to do that ... and why aren't we managing to do that ... and what do your service users think of being involved in your study and why don't ours feel like that ... a real kind of honesty ... around it so that it shifts into being something much more meaningful for everybody involved*

7/6/12 TMG

R11: *I have no doubt that you are both absolutely charming and supportive and manage it really well ... I am wondering about ... it's never too late to sit down and have an hour when we talk about .. what do you do if .. somebody .. loses their temper.. or there's a group dynamic or whatever ..*

### **6.4.3 Resources for involvement**

While vouchers and expenses were available for research partner contributions, none of the researchers had specified involvement responsibilities or time allocated to involvement work. Involvement activities were planned and conducted in addition to other research roles, and researchers were aware that this undermined their capacity to sustain involvement activities

when other research tasks had to be prioritised. Because most researchers worked on a number of studies, and some were also part-time, this problem was intensified. However, the trial was funded alongside other research studies on DV, and £30,000 was allocated for involvement across all the studies, including funding for staff time.

When I contacted the principal investigator about conducting my project there was a full-time trial manager who helped me to negotiate arrangements and research governance approval. However, by March 2012 she had left and a part-time trial manager was not appointed until August 2012; this gap had a significant impact on the workload of other members of the team. In addition, one of the research associates was ill for a long period, and trial recruitment in AG1 was suspended for a time. When new staff joined the team they needed a period of induction and time to build relationships with agency staff and research partners. Staff changes and capacity to support the trial in the agencies also added pressures to researchers' roles. The lack of staff with specific involvement responsibility and capacity issues in the research team were the most significant factors affecting involvement activity.

*8/1/13 TMG*

*R10: well .. we .. made an informal agreement which I think ... we all need to reconsider .. [R8] hasn't been convening those meetings ... and due to pressure of work asked me if I would take over convening the meetings .. [laughs] .. but owing to work I haven't done anything about it either ..*

### ***Payment***

Research partners were paid for their contributions with shopping vouchers and any out of pocket expenses were covered, travel was often by taxi. The voucher system was developed to reward research participants and adapted for research partners. Research partners were given £10 vouchers, but at AG2 they received double this amount because they were also paid by the agency for involvement in service provision. At two PPI meetings researchers forgot to give out vouchers which caused some awkwardness. Research partners appreciated the vouchers, but two of the four interviewed commented they would do the work whether or not they were paid.

Payment practices were not standard in the department, or even within the DV research group; vouchers of different values were given for involvement in other DV studies. Within the department other payment approaches were used and some research partners were paid fees, again rates differed between studies.

## 6.5 Context of involvement

The principal investigator had joined the department in 2007. The DV research group was expanding and during my data collection period three new studies were successfully funded. This was reported to research partners in the spring 2013 newsletter (D73).

Both the principal investigator and clinical psychologist had a commitment to doing research that was of practical benefit in the DV field and to improving links between health services and DV agencies. A prior study had resulted in the development of training for GP's to enquire actively about, and respond more effectively to, disclosure of DV, including making referrals to DV agencies; and funding had been secured for an implementation process. D25 provided a case study on this work and the report was described as aiming to

| *D25: capture compelling stories about improvement in practice.* |

The aim of the trial demonstrated the desire to increase access to psychological therapies for DV, and D23 (IRAS form) described how findings would be linked to policy recommendations and development of guidance for DV service commissioning. Plans for dissemination included working with public health colleagues, local authorities, DV agencies and service users as well as a seminar for government ministers. A focus on implementation was confirmed by others.

*R10: I think [R6] is quite atypical as an academic because he's very hands-on and the kind of projects we're running are very practical ... every time he does an academic piece of work he always runs an implementation project afterwards which is quite unusual*

The commitment to implementing research findings and improving services underpinned collaborative working with agencies and ongoing relationships with both agency staff and service users. The trial included resources for an implementation process and a commitment to disseminate findings to practitioners and service user as well as in academic journals.

### 6.5.1 Leadership

The principal investigator and the clinical psychologist had worked together on previous studies and reported commitment to involvement. While overall research leadership was clear, leadership in relation to involvement was expressed in underpinning values and attitudes and demonstrated by willingness to listen to research partners and respond to their suggestions. For example, the gap identified in research priorities resulted in two new research bids, and I observed lengthy discussions about the suggestion to use Facebook for retention. However, neither of the senior researchers had a hands-on role in organising

involvement, but the principal investigator led the first PPI meeting in AG1 and dropped in at the beginning of the second meeting there.

The two PPI groups differed in that the principal investigator and/or trial manager attended both meetings at AG1, but neither attended the meetings at AG2, which were both organised and facilitated by R8 with the support of R10. R8 formed and led the group at AG2. R10 attended all four PPI meetings and played a supportive and facilitative role.

*R8: I feel the responsibility is mine to set up the group and to organise the activities.*

Over time the trial manager took up a leadership role; she had prior experience of involvement and during the autumn of 2012 got in touch with research partners from AG1, and did preparatory work for the November 2012 PPI meeting there. She also initiated the Newsletter and prepared a briefing document (D69) for the DV research group meeting which considered the development of involvement across studies (see section 6.2.5).

*D69: Maintaining such groups is important and often overlooked as a cost. .. it is timely to consider what, as a group, we want to achieve ... a co-ordinated effort would be a really selling point [for development of the research group] ... [We need to] identify a person who has capacity to take this forward.*

In these ways leadership of involvement was shared in the research team during the conduct of my project, being provided by the principal investigator, the trial manager and R8. While the team experienced capacity issues there was some ambiguity about involvement responsibilities; the transfer of responsibility from R8 to R10 was not clearly agreed or actioned (see section 6.4.3).

## **6.5.2 Research/agency relationships**

Working within a university department researchers had no direct links to service users. Two of the senior researchers (R6 and R11) were health professionals but they did not have clinical roles in DV agencies in the area. Conducting research in DV therefore required building relationships with DV agencies and staff. The agencies were gatekeepers who could facilitate research and enable access to potential study participants and research partners. From the agencies perspective collaborating in research was described as supporting the development and provision of quality services for women, and as helping to maintain and build agency reputations in difficult economic conditions.

Working with agencies in this way meant that the principal investigator had to negotiate agreements with agency managers, and procedures to support research had to be developed that were acceptable to both researchers and agency staff. Day to day the research associates had most contact with agency staff. This included regular liaison to identify new potential



participants, the initial approach by agency staff and quick follow up by researchers for recruitment. Contacts also related to collecting information about ongoing contacts with trial participants from agency staff and follow up for retention. A health economist also spent time shadowing staff in the agencies collecting data about working practices so that the costs of delivering the trial intervention could be calculated. The clinical psychologist trained and supervised the agency staff who delivered the intervention to participants, and the intervention was also a new agency service which required new systems and management by agency staff. Therefore researcher-agency relations had a number of aspects (recruitment, health economics, and training and supervision of agency staff) and significant researcher time was required to support these aspects of researcher-agency collaboration.

TMG membership included staff from both agencies and issues about the conduct of the trial in the agencies were considered at every meeting. AG1 had collaborated with some of the researchers before, but links to AG2 were developed for the trial. During my project links were developed with a third DV agency to support a new DV study; as the number of studies on DV increased it was seen as important not to overburden any one agency.

While relationships with AG1 and AG2 were strong, collaborating in research meant additional work for agency staff. Agency staff changes and opportunities to receive the training to deliver the trial intervention had to be managed both by agencies and researchers. Turnover of agency staff meant that additional training to deliver the trial intervention was needed, which required significant additional input from R11. Involvement activities took place within these researcher-agency relationships, and interactions with agency staff also contributed to researchers' understanding of service user experiences.

### **6.5.3 History of involvement**

Within the university department there were different approaches to public involvement. Researchers specialised in different health areas and worked together in different configurations on different research topics. While there was involvement in many studies, policies and practices were developed within research groups in particular situations; there were no systematically shared policies or practices. Differences extended to different payment rates and processes. It seemed possible, if not likely, that no one in the department would know what public involvement activities were going on within all research studies. Another university department conducted research on closely related topics and there was involvement on studies there too, however involvement arrangements were made separately.

One newer DV study had recruited research partners from AG1 and AG2, and a third PPI group in another agency had been set up. Although DV researchers were considering more co-ordination of involvement, during my data collection period research partners did not have the chance to meet across PPI groups, across DV studies in the department, or between university departments, so there was no opportunity to develop a more collective involvement voice.

The principal investigator and clinical psychologist had worked together on another large DV study which had one research partner on the steering group. This was described by three researchers as a positive experience; the involvement role had evolved to include collecting interview data, and the research partner had subsequently found employment in the DV field. However, both R6 and R11 expressed reservations about having one service user on a study steering group and this experience influenced the development of PPI groups for the trial.

*R11: I think it was tough for [name] to manage it all on her own and there was a need for her of ... having some contact with other service users*

*R6: the fact that.. the researchers who come to the PPI group .. are always in the minority .. actually helps .. because of one of the problems for [name] .. I mean if we .. if we'd had a second [name] maybe it would have created a kind of critical mass on the [steering group] ... which would have shifted things .. but because it was [name] and eight researchers ... I think there was a structural problem whereas I am very aware in the PPI group .. maybe two of us go, sometimes three, but we are always outnumbered and that ... changes the dynamics*

While most DV studies in the department organised involvement through PPI groups, at least one also had research partners on a steering group.

#### **6.5.4 Relationships**

Many researchers were involved in running the trial, the TMG was routinely attended by the principal investigator, trial manager, clinical psychologist, qualitative researcher and research associates alongside two health economists, and other senior advisors attended from time to time. Some researchers contributed by teleconference. The emails circulation list was large and included four researchers who did not attend during my data collection period. Eight different staff members from the DV agencies attended meetings during my data collection period, four from each one.

Alongside the TMG there was a Trial Steering Group, and Data Management and Ethics Committee; in addition staff working on the trial met in other sub-groups which I did not observe. The trial research team was large (>25 people), and while the principal investigator and trial manager were involved in many groupings, some researchers only worked on

particular aspects of the trial. Several researchers on the trial worked on a number of DV studies in different capacities with other colleagues.

Within the TMG relations with between agency staff and researchers had periods of relative harmony and discord, which reflected fluctuations in agency capacity to focus on and support research alongside providing services, compounded by research team capacity issues. For a time one agency was in a better position to support research, while in the other things were more difficult, but over the data collection period this changed around.

Most researchers reported supportive team relationships, but inter-personal relationships between some researchers also revealed difficult dynamics at times. The sensitivity of this data means that it cannot be presented without compromising anonymity, but these issues were observed to affect the level of collaboration on involvement between colleagues.

*13/12/12 Research diary*

*I'm thinking that a lot of what affects PIR [public involvement in research] is the way that the research team works, relationships between colleagues, and the level of openness and support/tension between them*

## **6.6 Who was involved?**

This section reports findings about recruitment and legitimacy of research partners.

### **6.6.1 Recruitment**

In AG1 research partners were initially recruited from a service user involvement group at the agency.

*R6: the group was set up in 2008, so this is actually the ... the fourth year of the group ... they already existed as a group .. because they were also providing the .. some advisory function to [AG1]*

In AG2 R8 recruited service users and ex-service users through agency staff because there was no agency involvement group in place, and this was a challenge.

*R8: That was hard. Because I am dependent on [AG2] as the .. gatekeepers of women's information, so actually the leg work involved in setting up the group was quite extensive ... I had a long list of women ... their names and numbers had been put forward with their permission from workers and then many of them were then really difficult to get hold of. So ..the practicalities about accessing this client group were just really difficult*

Additional women were recruited to the PPI groups over time as a result of researchers' on-going contacts with agency staff and service users. At the PPI meeting in AG1 in November 2012 there was discussion about extending group membership.

AG1 PPI meeting 28/11/12

R12: ... whether you think .. there are other women that might want to be involved ... any thoughts?

RP7: ... Maybe more that have left recently .. or are still here sort of thing ... .. yea maybe just people that .. are using it at the moment cause we've all left haven't we [mms] ...

When researchers met to review involvement in the DV group in February 2013 there were suggestions that membership could be extended, for example, to include women who had not accessed DV agency services. The trial manager noted that if the focus of DV research expanded to include some issues, for example forced marriage, the membership of PPI groups would need to reflect such experiences. The principal investigator identified a regrettable gap that men's health groups had not been involved.

*R6: we actively went out.. to see if [we] could get some input from... men's groups .. that were meeting around health.. but .. we tried to arrange a meeting and they never came back to us .. and in the end we thought well ... we've tried hard enough ... [but] I think it's .. a defect .. that we haven't managed to identify a group of men.*

### 6.6.2 Legitimacy and representation

There were no problems in identifying the 'right' people to involve in this case study; DV service users had relevant experiences for the trial. Although some of the research partners in AG1 had been involved for several years, and were no longer using DV agency services, no concerns about legitimacy or professionalisation were expressed. Researchers identified a need to draw on specific experiential expertise for particular studies, so legitimacy was clearly associated with relevant experience.

R6 expressed caution about contact from members of one campaigning organisation, and reflected on the difficulty of involvement of male perpetrators in DV research.

*R6: we were actually approached by one of those [campaigning] groups .. when they heard about the [research] and we asked them if we could meet with them ... and then they never got back to us .. and we didn't push .. to be honest ... because we found those groups a bit .. worrisky*

*R6: .. working with perpetrators is difficult .. so the proxy for that is that is that our partner .. in [name of group of studies] is [organisation name] .. which is the organisation that .. accredits and develops training programmes for perpetrators ... these organisations act as proxies for PPI .. when the PPI input may be problematic ... is it ideal? No.*

### 6.7 Power

Researchers remained in control of research; involvement was not oriented to the transfer of power to research partners but to improving the design, conduct and outcomes of research. However, researchers sought input from research partners on research priorities and acted on identified gaps. Research partners' contributions in PPI meetings were dependent on

researchers to identify tasks and issues for consideration, and meeting agendas were set by researchers. However, there was some space in meetings for broader discussions which allowed unanticipated contributions to emerge. Research partners expected researchers to seek input as and when they needed it, and for their contributions to address researchers' needs, where involvement was subordinate to research. Willingness to get involved signalled motivation to help other women and improve services and care, with trust in, and respect for, researchers' expertise and skill. Such attitudes were underpinned by an acceptance of expert power, not a challenge to it, where researchers and women were working together with shared goals and interests.

Research partners expressed no desire to be in control of research. The impression that training was about becoming a researcher was seen as funny and ridiculous by one research partner.

*RP7: I thought it was training you how to be a researcher ... that's what I honestly thought [laughter] I thought like in a years' time I am going to have [principal investigator's] job*

Power dynamics were modified by holding meetings away from the university department, by the balance of researcher and research partners present, and by informal and hospitable norms. Research partners were also encouraged to be critical of researchers' ideas and documents. However, separation of involvement from research management meetings meant that research partners were at more distance from researchers' power, with less opportunity to gain a deeper understanding of the conduct of research.

The potential for more service user power through involvement was acknowledged by the principal investigator, but current systems were viewed as constrained and relatively unthreatening.

*R6: we've been on the road in the foothills for too long ... we've talked the talk, we don't walk the walk ... and I think the way that PPI is configured at the moment it's not threatening, it's contained, but it actually has the potential to be [stronger] ... .. and despite me being slightly cynical about the box on the NIHR applications actually I am really glad the box is there because ... it's made us think much more about.. hang on.. what are we really doing*

Working with DV agencies as research collaborators represented a sustained effort by researchers to connect research more strongly to service providers, service users and potential research participants. The principal investigator was active in the development of national policy. Research plans included a focus on the implementation research findings, and previous DV research had successfully led to the commissioning of training for health professionals on

DV based on research findings. Therefore, the DV research group was developing capacity to support better understanding of DV across the policy/research/care system, where involvement was one part of a broader system which had potential to generate research evidence grounded in user experiences, based in the realities of DV agency provision of services, with links at a policy level.

## **6.8 Conclusion**

This chapter has presented findings from the domestic violence case study. The next chapter compares the case studies and discusses the findings in relation to current involvement debates.

## **Chapter 7: Comparison of case studies, reflection and discussion**

### **7.1 Introduction**

This chapter brings together the findings from the case studies, compares them and considers their implications in relation to relevant involvement literature, including the key critiques and issues identified in the literature review. The discussion considers the implications of the findings for the connection between theory and practice in involvement in research.

### **7.2 Involvement tasks and roles**

A key focus of the project was to identify what research partners and researchers were doing when they worked together. This section considers the involvement tasks and roles described in the case studies and their implications for understanding the involvement role in health services research, including considering connections to the rationale for involvement.

#### **7.2.1 Involvement tasks**

The need for involvement early in the research process is stressed in the involvement literature (Staley 2009; Brett *et al.* 2010; Shippee *et al.* 2013), and in guidance (INVOLVE 2012b). In both case studies involvement in the design of research was described in research funding and governance documents and was reported by participants. In the rheumatology case study a research partner had reviewed the lay summary and study documents. In the DV case study involvement had focused on trial design, follow up procedures, and participant information, alongside consideration of how best to explain the research to potential participants. In the DV case the PPI groups had also contributed to the design of other DV studies being planned in the department, including reviewing participant information.

Both case studies also demonstrated that researchers were interested in, and willing to pursue, research priorities of importance to patients and service users, which is acknowledged as an important area for involvement (Oliver *et al.* 2004; Entwistle, Calnan and Dieppe 2008). Research priorities in the rheumatology department demonstrated a strong and ongoing focus on issues prioritised by patients, including fatigue and problems with feet, alongside the development of patient reported outcomes. The study at the centre of the rheumatology case built on preceding research. Patient priorities were central and prior findings were systematically developed, with potential for further related research dependent on study findings. Involvement in the design of the trial in the DV case study identified a gap in research which led to the funding of two new DV studies.

During the conduct of research, research partners continued to review study documents. In the rheumatology case this included commenting on the wording and layout of the new outcome measure a number of times. This process was central to the content of the study. In addition, documents explaining research processes were reviewed alongside consideration of practical arrangements for data collection in all phases. In the DV case study involvement mainly focused on recruitment and retention of participants, including incentives for participation and a range of strategies were reviewed. In this case the PPI groups also contributed to the conduct of other studies, including doing pilot interviews, reviewing documents, advising on recruitment and other study practicalities.

In the rheumatology case, research partners had contributed to a study summary of findings for dissemination to participants. This goes beyond what is recommended during dissemination by Brett *et al.* (2010) and Telford, Boote and Cooper (2004), and the rheumatology case study met two of the three critical appraisal criteria for dissemination provided by Wright *et al.* (2010): involvement in the writing of publications and dissemination to participants and service users.

Funding and governance documents in the rheumatology case study described involvement in the consensus process (phase 1), analysis of qualitative data in phase 2, and dissemination of findings. Involvement did take place in phase 1 and had started in dissemination of findings, but while there was involvement in the discussion of how quantitative data would be reported, there was no involvement in qualitative analysis in phase 2. Funding and governance documents in the DV case study also described involvement in the management, analysis and dissemination of the trial. There was no involvement in the quantitative analysis of trial data, or in the qualitative analysis of data collected on participants' experiences of the intervention. Involvement in data analysis was, therefore, described in funding applications and research governance documents in both case studies but not conducted. This finding suggests that the monitoring of involvement activities against involvement plans in formal documents might be a fruitful way of evaluating involvement, and further investigation of gaps between plans and practice may be useful.

Formal documents in both cases put a positive gloss on involvement plans, and descriptions of involvement implied, rather than directly stated, research partner support for the funding applications. In my view, the legitimating role of involvement in funding bids would benefit from being more overt. Making it clearer to research partners that they are being asked to endorse researchers' plans when they contribute to the design of studies could increase their understanding of this process and their capacity for influence.



In both cases involvement took place, and was planned, across the research cycle, but it was also intermittent. The timing of involvement in the rheumatology case reflected different phases of the study and there was a gap in involvement once the measure had been finalised and was being tested in phase 3. In the DV case PPI meetings were planned to be biannual, and four meetings took place over my data collection period but at varied intervals. In both cases there were periods when no involvement took place, and research partners in both cases identified a need for recaps and reminders about studies. Involvement 'throughout' a research study has been described as positively influencing the impact of involvement, because research partners have been involved from the start and have a greater sense of ownership and commitment to the research (Gracia, Blasco and Andradas 2011). Involvement throughout has been contrasted with involvement at discrete stages of research (Staley 2009). In this project, there was both involvement in most stages of the research cycle, therefore involvement throughout, and also gaps in involvement. This suggests that the term 'involvement throughout' is open to different interpretations, with implications for its association with impact.

Authors have reflected on involvement in different kinds of studies. The need for increased involvement in identifying and generating outcome measures has been identified by Staniszewska *et al.* (2012). The research design in the rheumatology case study was an innovative method of involving expert patients in outcome development; Rose *et al.* (2011) reported another new methodology for deriving outcome measures in mental health research based on strong involvement. In 2001 there was no publicly available information about the nature and extent of involvement in randomised controlled trials in the UK (Hanley *et al.* 2001), but ten years later Boote, Baird and Sutton (2011) identified nine papers reporting involvement in trials. The main contributions of involvement reported were: review of consent procedures and patient information sheets; suggestion of additional trial outcomes; review of trial data collection procedures; and recommendations on the timing and location of trial follow-up data collection. Involvement in the DV case addressed many of the tasks identified by these authors, although it did not include review of trial outcomes. However, plans included involvement in the dissemination and implementation processes following the trial, which was not reported by Boote, Baird and Sutton (2011).

A range of involvement tasks in relation to the design, conduct and dissemination of research were identified in the case studies which have been identified in reviews of involvement in research (Staley 2009; Brett *et al.* 2010; Shippee *et al.* 2013). The practice of involvement in

the case studies therefore confirms existing evidence that similar involvement tasks were identified and undertaken in different contexts and for different kinds of studies.

### **7.2.2 Involvement role**

In both case studies the core of the involvement role for research partners was a willingness to speak up and share relevant experiences and views, and it was understood that talking about personal experiences could be demanding. The role also included reading and commenting on research documents. Research partners did not know what involvement jobs would be coming next, but this was not a problem for them; they trusted researchers to seek their contributions when appropriate. The involvement role in the case studies was therefore responsive rather than proactive, and contributions were sought and guided by researchers' technical understanding of research and their interpretation of the role. These findings suggest that the involvement role is likely to be reliant on researchers understanding of involvement.

Research partners in the DV case found their role straightforward. Researchers felt that the length of the trial restricted the role, but they anticipated more scope for involvement in the interpretation and dissemination of findings. There were terms of reference for the PPI groups but the role was not specified in any detail. The role of both groups included contributing to other research studies within the department. In AG2 the PPI group also contributed in relation to DV agency service provision; this was seen as a mutually beneficial arrangement by researchers and agency staff, with additional payment for research partners. The researcher role included organising PPI meetings in both DV agencies, and making meetings welcoming, friendly and informal. At least two researchers attended every meeting, one took a lead but facilitation was shared. Qualitative research skills were seen as transferrable to involvement.

In the rheumatology case study the new research partner found contributing in research meetings more demanding than she anticipated. Experienced research partners also reported similar initial anxieties, and that it took time to build confidence and contribute. Some researchers also provided clinical care to research partners, so involvement required navigating between clinical and research roles. Health professionals and research partners both reported that this had been challenging and that appropriate boundaries had been negotiated over time. The involvement role for researchers required leadership to set meeting norms and facilitation skills. Key aspects of facilitation skills identified were making meetings inclusive, explaining technical terms, and making complex ideas accessible without being patronising.

In both cases the researchers' role included the need to be aware that involvement might trigger vulnerability or distress (see section 7.4.2 for further discussion of support issues). Neither case study provided job descriptions, but despite this research partners contributed effectively and the essence of the role was clearly understood. In the rheumatology case study the consultant nurse reported that they no longer thought it helpful to provide job descriptions for involvement because the role sounded difficult and could put patients off getting involved. Instead, providing on the job support and training to take on different roles was recommended.

The description of a responsive, rather than proactive, involvement role and the finding that role descriptions might put off potential research partners, do not suggest that research partners either wanted, or would necessarily benefit from, role clarification. This contrasts with Cotterell *et al.* (2010) who found that the aims of involvement activities were often unclear to research partners involved in cancer research, and identified a need for the role and remit of user groups to be specified. Other authors have emphasised the need to clarify the involvement role (Telford, Boote and Cooper 2004; Brett *et al.* 2010; Wright *et al.* 2010; Shippee *et al.* 2013). Brett *et al.* (2010) have described negative impacts of involvement on researchers relating to poor understanding of research partner roles and contributions; this suggests that it may be researchers who need improved understanding of the potential of involvement. However, researchers in the case studies did not report such problems.

Providing a job description could also contribute to the professionalisation of research partners, which has been identified as potentially undermining the credibility of experiential expertise (Thompson *et al.* 2012), and may make the desirable aim of more diverse involvement (Robinson, Newton and Dawson 2012; INVOLVE 2012c) more difficult. There is a dilemma for involvement; the absence of job descriptions leaves inexperienced researchers and research partners without guidance, but job descriptions may put potential research partners off, particularly those who do not usually volunteer.

### **7.2.3 Connecting task, role and purpose**

The literature review identified a range of different potential purposes of involvement with implications for the involvement role (Cayton 2004; Dyer 2004; Bochel *et al.* 2008) and findings showed that the normative and substantive rationales are oriented to different outcomes. However, within the case studies the purpose of involvement was not contentious and nor was it the topic of discussion. The tasks and role addressed expressed an implicit understanding that involvement was intended to improve research, including design, conduct and dissemination. Research partners' motivation for involvement was clearly associated with a

desire to help others with similar issues, with the aim of to improving care and services, so this understanding was not imposed by researchers. Researchers' and research partners' actions and accounts demonstrated a shared motivation to improve services and care through research. As such involvement was overwhelmingly oriented to the substantive rationale for involvement. However, there were limited overlaps with more political purposes, for example, reference to involvement in funding and governance documents legitimated research applications, and in the rheumatology case study there were accounts of patients lobbying the hospital on behalf of the department.

The case studies demonstrated that researchers and research partners could make sense of the involvement role and tasks, based on an implicit shared understanding of the purpose of involvement. The controversy in the involvement literature about the purpose of involvement had no resonance with the practice of involvement in the case studies. A reactive involvement role dependent on researchers' technical understandings of research reflects the orientation to the substantive rationale, and implies that the criteria for evaluating involvement in the case studies should focus on outcomes on research, not on the outcomes valued by normative involvement related to democracy and social justice.

### **7.3 Impact of involvement**

This section considers the outcomes or impacts of involvement on research and on research partners and researchers, and reflects on the impacts reported in relation to the literature and theories of involvement.

#### **7.3.1 Impact on research**

Impacts were reported on the design of the research in both case studies. In the rheumatology case the lay summary was made more accessible. In the DV case the trial design, including 1:1 randomisation to intervention and control groups, was approved by research partners, as was follow up of participants for a year, subject to safety concerns being addressed, even though this was not agency policy. Study information was improved in both layout and accessibility.

In the rheumatology case involvement improved documents supporting consultation meetings and the layout and wording of drafts of the outcome measure, which we reviewed by the research partners several times in the course of the study. However, many contributions to the content, wording and layout of questions – crucial issues in the development of the measure – were made by the expert patients who were study participants. Impact was also

reported on research procedures which included adjustment and approval of practical arrangements for the running consultation meetings.

In the DV case review of the verbal approach to participants helped researchers understand potential participants' situations, improved researcher confidence in describing the trial, and supported the use of mobile phones in communication. Recruitment and retention strategies and processes were reviewed, and approval from research partners helped researchers balance the drive for numbers with participants' needs. Strategies to address retention problems were identified and considered, though not all were adopted. Research partners also reviewed and approved modified incentives for participants to return follow up questionnaires.

In the rheumatology case study a team meeting considered which findings should be reported in journal articles on the study, and one research partner contributed to these discussions including the presentation of statistical findings. Both research partners in this case provided feedback on a draft summary of study findings for research participants.

These impacts reflect many impacts of involvement in research reported by Staley (2009) and Brett *et al.* (2010). Boote, Baird and Beecroft (2010) reported a range of impacts at the design stage of primary care research, including contributions to patient information, review of acceptability of data collection procedures, and the timing of recruitment and follow up to studies, which echo impacts identified in the case studies. Marsden and Bradburn (2004) and Ali, Roffe and Crome (2006) reported some negative effects of involvement on trial design but there were no such negative effects of involvement reported in the DV case. Staley (2009) described how involvement helped researchers adjust their research tools and methods to suit participants, including making documents more accessible (Smith *et al.* 2008). Involvement in recruitment was reported to make procedures more sensitive to the needs of participants by Bryant and Beckett (2006). The positive impact of involvement on study recruitment has been confirmed by Ennis and Wykes (2013) who found that mental health studies that involved research partners to a greater extent were more likely to have achieved recruitment targets, for the first time associating patient involvement with study success. Smith *et al.* (2008) report that involvement helped to make sure that research methods were workable, but that users were rarely involved in the writing of publications; however, one research partner in the rheumatology case study had co-authored 22 articles. The findings therefore reflect a similar range of impacts as have been identified in other research, so the range of potential impacts that have been identified to date may now be relatively comprehensive.

A number of involvement tasks took the form of review processes where researchers presented ideas, documents or plans to research partners for discussion, where the outcome was approval of researchers' proposals. Such review processes were particularly important in the DV case study, for example, providing service user perspectives on the acceptability and ethical implications of randomisation and follow up. This kind of involvement does not necessarily result in tangible change, but in my view these processes helped to safeguard participants and therefore contributed to the quality of research. However some authors, for example Wright *et al.* (2010), emphasise that evaluation of impact should focus on what difference it has made to a study. In these terms the impact of review and approval processes would be described as limited because no tangible change resulted. This highlights a difficulty in evaluating the impact of involvement, and the need for improved conceptualisations of outcomes which address different kinds of contributions with different kinds of outcome.

### **7.3.2 Impact on research partners and researchers**

All research partners interviewed reported gaining satisfaction from their involvement roles and overall experiences were described positively. Research partners described increasing confidence, in their role and more generally in their lives, and improved self-esteem. Research partners in the DV case study described meetings as supportive and friendly, where they could be themselves and were appreciated for their contributions; such experiences were valued following experiences of violence and abuse. In the DV case research partners appreciated meeting and working with others with similar experiences. In the rheumatology case study there were significant cumulative positive impacts for some research partners who had been involved for many years, including improved coping with their condition. Research partners wanted to improve services and care, and appreciated the opportunity to give something back or help others. Similar altruistic motivations have been reported by research partners involved in cancer research (Thompson *et al.* 2014).

In the rheumatology case study negative impacts were identified by both research partners and researchers over time which resulted from being exposed to information about their condition which led to unwelcome awareness. In both cases negative impacts were associated with recalling difficult experiences which could lead to distress. The potential for involvement to trigger flashbacks was also reported in the DV case study.

These impacts on research partners reflect impacts reported in the literature which have included an improved sense of well-being, self-esteem, and confidence (Minogue *et al.* 2005; Staley 2009; Brett *et al.* 2010; Cotterell *et al.* 2010). Staley (2009) reported research partner benefits of making new friends and supportive contact with others like them. Cotterell *et al.*

(2010) reported motivation focused on wanting to give something back and improve care for others in involvement in both cancer care and research, and positive impacts were reported on living with cancer. Hearing negative information about cancer and potential prognosis could have a negative impact. However, these authors also found that relationships with professionals could be challenging which was not a finding in this project.

Williamson *et al.* (2010) describe significant personal and social impacts of involvement based on a case study of the research career trajectory of two lay researchers. Impacts reported were substantially increased confidence, a sense of personal achievement and changes to identity. Some similar impacts were reported by the three experienced research partners in the rheumatology case study. Thompson *et al.* (2014) suggest that the impacts reported in the literature have overlooked the importance of involvement in providing space for identity work, where some people in their study were found to actively redefine aspects of self and identity. These authors suggest that involvement promotes narrative repair that can be needed when chronic illness strikes. This was reflected in the account of one research partner in the rheumatology case study, who directly connected experiences of involvement with positive changes to identity.

Researchers reported that involvement motivated them and kept them connected with the importance of research for patients and service users. The effects on researchers reported by Staley (2009) included enjoyment and satisfaction and challenges to beliefs and attitudes, but did not include motivation. Brett *et al.* (2010) identified 33 papers reporting impacts on researchers, 15 reported beneficial impacts and 26 reported negative impacts. Some negative impacts on researchers were linked to scepticism about involvement. Negative impacts on researchers have also been associated with changes to working practices (Howe *et al.* 2006); however, changes to meeting norms in the rheumatology case were not reported as problematic, although the head of department acknowledged that meetings took longer.

The case studies have identified a range of positive and negative impacts on research partners and researchers which echo findings from other studies, confirming the types of impacts on people that can be associated with involvement. The literature review highlighted the importance of the rationale for involvement for the evaluation of outcomes, which suggests the need to consider the impacts identified in the project from this perspective. The case studies were associated with the substantive rationale, and in the rheumatology case positive impacts of involvement on research partners were seen as valuable but unanticipated benefits of involvement by the head of department (see section 5.3.2). Neither was it clear that involvement in the DV case study intended to produce outcomes for research partners.

Orientation to this rationale emphasises the evaluation of impacts on research, and while impacts on people are widely reported in the literature, their status becomes unclear if substantive involvement does not aim to produce such impacts. Therefore, although research partner benefits were valued by both researchers and research partners, in relation to the substantive purpose of involvement in the case studies perhaps they should be understood as secondary or unanticipated benefits. However, if substantive involvement were planned to produce research partner impacts then such impacts would have a different status, and in normative involvement such outcomes may be strongly aligned with intended aims.

Whether or not personal impacts are to be understood as central or incidental to involvement is contested in the literature, for example, the measure developed by Morrow *et al.* (2010) is focused entirely on the evaluation of research partner empowerment and experiences of involvement, based on the assumption that such features of involvement indicate its quality. Here research partner outcomes are central to the evaluation of involvement practice. However, Wright *et al.* (2010) do not include impacts on research partners in their critical appraisal criteria, and Ives, Damery and Redwood (2012) describe impacts on research partners as incidental. Reviews of impact by Staley (2009) and Brett *et al.* (2010), and the public involvement impact assessment framework (Popay and Collins 2014), do not address the question of the relative value and desirability of different impacts in relation to rationale, although Popay and Collins (2014) do propose consideration of the values underpinning involvement.

Drawing attention to rationale establishes the need to consider impacts in relation to the aims of involvement, which raises a problem when involvement leads to unanticipated outcomes. Current conceptualisations of impact do not address these issues, so findings indicate further need for theoretical development to refine the evaluation of impact.

### **7.3.3 Additional impacts identified**

In addition to the impacts discussed in the previous sections, additional impacts of involvement were reported. In the DV case involvement in the trial design resulted in the identification of a research priority focused on the impact of domestic violence on children that had been missed by researchers. This led to the development of two research bids which were successfully funded. In the rheumatology case study participants reported that two research priorities had been identified as a result of involvement in the department in the past – the importance of fatigue and foot problems for patients. This had resulted in the development of new areas of research, and findings were being adopted in guidance for best clinical practice. The case studies suggest that that involvement has potential to identify



research priorities of significance for research, treatment and care. However, these impacts were unanticipated additional benefits of involvement.

Cumulative impacts of involvement over time were also identified in the rheumatology case study across the domains of research, patient care and health professional education. Involvement was associated with changes to patient-health professional relations, and improvements to treatment and care, including the provision of a new foot clinic. The long-term impact described included changes to the ethos of the department, and establishing norms and working practices which supported involvement, see section 5.5.3. Involvement in the department was connected internationally. Lessons learnt from involvement in outcome conferences have been published (de Wit *et al.* 2013a) alongside significant impacts on outcome research (de Wit *et al.* 2013b); patient leadership at these conferences was provided by research partners from the department (section 5.5.1). Such cumulative impacts suggest that involvement promotes positive cultural change, but that such changes need to be sustained over time to become embedded. The long-term leadership of the head of department and the consultant nurse, alongside experienced patient partners, was a key factor in these changes as reported in section 5.5.1. The head of department described changes resulting from involvement in the outcome conference as astonishing and unpredictable impacts of involvement (section 5.3.3.).

In addition, the impact of involvement in the rheumatology case might be connected to the contributions of expert patient participants which were very significant for the study (see section 5.2.2). Experienced research partners were chosen for this participant group, so their impact as participants was partly based on involvement experience. The study at the centre of this case also directly addressed outcomes that patients had prioritised in prior research, and conducting research oriented to patient priorities was connected to the ethos in the department, so might be seen as another long term impact of involvement. Such issues blur the distinction between impacts of involvement, findings based on participation, and long term impacts of involvement in research.

The additional impacts described in this section raise have implications for the evaluation of impact. Impacts were identified on research priorities, and cumulative impacts across domains of involvement over time, alongside impacts related to involvement in the proceedings of an international conference. The range of potential impacts confirms that evaluation of outcomes needs to consider different types of impact, and impact over the long term. Several of these impacts were unanticipated benefits of involvement, raising similar problems for the

status of such impacts as has been identified in relation to unanticipated impacts on research partners.

#### **7.3.4 Feasibility of impact assessment**

Although a range of impacts were identified, the findings also confirm that it is difficult to identify and record impacts of involvement. Researchers in the rheumatology case study found this difficult (see section 5.3.1) and my research methods did not wholly resolve this problem. One difficulty was the result of research partners being integral members of research teams, where the outcome of meetings was the product of group discussions where individual contributions were not necessarily identified. Researchers reported some involvement impacts as memorable, but many were described as more subtle, and despite implementing a process to record the impact of involvement, little feedback was received by the involvement co-ordinator. Despite the ethos of involvement and recognition that establishing the impact of involvement was important, researchers still found it difficult to identify and record impact.

Although my research methods included observation and the collection and analysis of documents it was still difficult to link involvement activities directly to impacts. While the notes of one team meeting conducted in the rheumatology case, and observation of a second meeting, provided a record of research partner contributions, what subsequently happened as a result of these contributions was difficult to track. Similarly, even though many discussions about involvement were observed in the DV case study, and actions were recorded and followed up in notes of meetings, analysis of such data did not necessarily provide evidence of impact. Tracking specific impacts on documents would have required access to all different versions, before and after involvement which was not possible. Even when I was able to collect drafts of the measure being developed in the rheumatology case study, which included research partner comments, it was not possible to track subsequent specific changes.

As a result, evidence of impact was more dependent on accounts of involvement than I had hoped. To collect more evidence of impact, would require access to research processes and documents to a level of detail that is unlikely to be practical. The limits I encountered to data collection, and the problems reported by researchers in the rheumatology case study, therefore confirm that recording and evaluating the impact of involvement is challenging, as identified by Barber *et al.* (2011) who found that it was not feasible to evaluate the impact of involvement on research design, managing research, collecting data, analysis or interpretation of findings.

The systematic evaluation of impact is a concern of academics interested in involvement, whereas many researchers and research partners are likely to want a simpler process. In both cases research partners wanted feedback about the impact of their involvement on research. It is unrealistic to expect all health researchers and research partners to provide detailed evidence of impact because tracking and recording many research processes in detail would be very onerous. While the impact assessment framework developed by Popay and Collins (2014) provides a sophisticated approach to the assessment of impact which addresses the needs of academics, it includes a two stage process each with several component parts, which would need significant resources, and might extend the time needed to conduct research. Given reports from researchers of negative impacts due to time and cost implications of involvement (Brett *et al.* 2010) this framework may be unrealistic for the assessment of impact in many involvement situations where there are no additional resources allocated to the evaluation of involvement.

### **7.3.5 Reflections on impact assessment**

The impacts reported in the case studies reflected findings in the reviews of impact conducted by Staley (2009) and Brett *et al.* (2010) which have confirmed that involvement in research does have a variety of impacts on research, research partners and researchers. Brett *et al.* (2012) concluded that their study provided the first international evidence of the positive impact of involvement on all key stages of the research process and that it enhanced the quality of research and ensured its appropriateness and relevance. My project contributes to the growing evidence base in this area.

Additional impacts of involvement were identified on research priorities in both cases, and cumulative impacts were identified in the rheumatology case study across domains of involvement and over time. Unanticipated outcomes included identifying new research priorities, and impacts on research partners. While linking the evaluation of involvement with rationale and related outcomes should improve impact assessment, findings have identified that there is a problem in assessing the status of unanticipated impacts. Impacts on research partners could be understood as secondary in this project, because neither case study overtly aimed to produce such impacts. However, the status of such impacts is contested in the literature, and impacts on research partners can be desirable in either normative or substantive involvement. The absence of a stated rationale and aims makes it difficult to evaluate the relative importance of different kinds of impacts, but the unanticipated impacts identified were important for research and of value to research partners.

Although many authors emphasise the importance of assessing the impact of involvement, the conceptualisation of impact needs development. While Staley (2009), Brett *et al.* (2010) and the PiiAF framework (Popay and Collins 2014) include the identification of impacts on research and on people, both positive and negative impacts, and long and short term impacts, they do not suggest how to account for impacts where review does not result in any change, or for the potential that involvement might have impact by stopping things happening. Nor is impact considered cumulatively across different involvement domains. In particular, the assessment of impact is not clearly linked to the rationale or aim of involvement, which makes distinguishing between intended and unintended outcomes difficult. However, within the PiiAF framework (Popay and Collins 2014) such issues could potentially be identified in the production of an impact assessment plan.

While the need to evaluate the impact of involvement is a key theme in the literature, it is not uncontested. Purtell and Wyatt (2011) express concerns that important issues are missing from the debate about the measurement of impact in research, including understanding who benefits from such assessment, what criteria are appropriate, and when such criteria should be applied. Purtell, Rickard and Wyatt (2012) also question whether evaluation of impact is appropriate, because of the lack of agreement about the purposes of involvement, and problems in learning from existing evaluations. These authors challenge the desirability and appropriateness of impact assessment for involvement in research. However, research partners were interested in the impact of their involvement, and researchers in the rheumatology case wanted to identify impacts of involvement in their department.

The findings confirm that it is difficult to identify and record the impact of involvement, and therefore reinforce concerns about the feasibility of impact assessment. Conducting observations and analysing documents did wholly overcome this difficulty, although a range of impacts were identified. However, the methodology of this project did support a focus on the broader context of involvement, which alongside the presentation of analysis by case, has supported the identification of a wide range of impacts in the case studies. My project has added to the evidence base on the impact of involvement, and identified the need to develop the conceptualisation of involvement to improve evaluation.

## **7.4 Involvement processes and mechanisms**

This section reflects on the involvement processes and mechanisms that were important in the case studies, and their relationship to the key involvement processes identified in the

literature review. The section goes on to compare features of the two involvement mechanisms, and reflect on resources and training and support.

#### **7.4.1 Important involvement processes**

Both case studies reported the importance of researchers being friendly, welcoming and appreciative. The new research partner in the rheumatology case study had not received the usual induction from the involvement co-ordinator, but she was supported in the research management meeting she attended by the presence of a more experienced research partner who contributed and was taken seriously. At the meeting I observed the chief investigator was available early to welcome the research partner and stayed on at the end to talk informally. In the DV case study involvement meetings were reported and observed as informal, welcoming and friendly and included provision of drinks, snacks and lunch with time for research partners to talk informally.

In the rheumatology case study the facilitation of meetings was the most important way that research partner contributions were encouraged, and researchers needed to clarify any use of jargon, explain research in accessible ways, and encourage questions for clarification. These processes helped research partners to develop confidence and understanding of research. In the DV case study involvement meetings were facilitated by two or more researchers, who supported each other by asking clarifying questions and encouraging research partners to contribute. Contributions and discussions flowed freely, and researchers actively encouraged research partners to be critical.

In both case studies research partners were given both verbal and written information about the research, and the provision of appropriate information supported involvement. This included a variety of study documents, agendas and notes of involvement and research meetings. The research partners in the rheumatology case had received and discussed the study protocol at the start of involvement. Research partners in the DV case reported that it would have been more helpful to have documents in advance of PPI meetings to allow them to give more considered feedback.

Research partners in both case studies identified a need for reminders and recaps about research studies, because gaps between meetings were likely to be several months, and research partners did not always attend all meetings. In addition, findings confirmed the need for researchers to give research partners feedback about study progress, and on involvement issues that had been discussed, including the impacts of involvement. Giving feedback was understood as a way of valuing contributions. In the DV case study this included feedback on

studies being conducted across the research group, and gaps in involvement were addressed by providing a Newsletter for all research partners. The importance of feedback processes have also been identified as important in the literature by Shippee *et al.* (2013) and by Evans *et al.* (2014).

These involvement processes supported good communication and relationships between researchers and research partners. Researchers treated research partner contributions with respect, and research partners felt valued. The importance of developing such researcher-research partner relations has been reflected by Brett *et al.* (2010) and Evans *et al.* (2014), and good relationships have also been associated with successful involvement (Elberse, Caron-Flinterman and Broerse 2010). Two involvement processes have been identified in the findings that have not been stressed previously, the need for recaps and reminders about research, and the benefit of encouraging critical comments.

#### **7.4.2 Support for research partners**

Both case studies identified that involvement had the potential to cause negative impacts for research partners connected to recalling and sharing difficult personal experiences. In the rheumatology case negative impacts were also related to finding out information about their health condition which was unwelcome and triggered distress. Participants in this case identified the need to be aware of potential support needs following some research meetings, and provision of support was based on established relationships, underpinned by clinical care of research partners as patients. The involvement co-ordinator could also be a source of support.

In the DV case distress was reported when recalling the impact of abuse on children, and the potential for memories to trigger flash-backs. While research partners wanted researchers to respond, for example by providing some support and telephoning later, or asking a DV agency worker to do this, they did not feel it was a researcher's job to provide ongoing support. One research partner saw triggering flashbacks as inevitable from time to time following abuse, and dealing with such memories as part of the healing process. While these examples of distress were reported, no lasting distress was observed in involvement meetings. Although support needs were identified by both researchers and research partners, and discussions in the TMG about support mechanisms identified some complicated issues about the provision of support by DV agencies, this issue was not followed up as planned. The provision of support for research partners is emphasised in the literature as an important involvement process (Wright *et al.* 2010; Brett *et al.* 2010), and Telford, Boote and Cooper (2004) included the provision of mentors for both support and supervision. While the need for such formal processes of

support was not identified in the project, the DV case demonstrated that there was potential for distress. Ad hoc support processes would therefore have benefitted from further development, as discussion in the TMG outlined.

### **7.4.3 Comparison of involvement mechanisms**

The mechanisms of involvement differed; in the rheumatology case study research partners contributed to research team meetings, which were the management mechanism for the study, whereas in the DV case the PPI meetings were set up separately and specifically for involvement.

Features of the involvement mechanism in the rheumatology case study were:

- Professionals outnumbered research partners and meetings took place in a research environment
- Meetings addressed all research issues needing consideration, including methodological, technical, theoretical and management issues
- Researchers were contributing predominantly as academics and health professionals within their areas of expertise
- Facilitation of involvement was woven into the academic process
- Because professional and academic meeting norms don't generally support expression of experiential expertise, facilitation of involvement was not only to enable research partners to contribute, but also to support a different kind of contributions from the professionals present.

The infrequency of team meetings meant that involvement was intermittent, but this mechanism was supplemented by additional meetings and other contacts between researchers and research partners.

This mechanism demanded more of both lead researchers and research partners. Research partners needed time to build confidence, and encouragement, to contribute. Facilitation of involvement was a key researcher skill; the consultant nurse described facilitation and leadership in meetings as determining the difference between active involvement and tokenism. This mechanism required adjustments to research meeting norms and strong leadership. Abelson *et al.* (2004) found that experienced citizen participants stressed the need for impartial facilitation of involvement in health policymaking, alongside the importance of getting information and communication processes right. Leamy and Clough (2006) reported difficulties in balancing researchers expert role with a facilitative role, suggesting this could be

a challenging combination. This difficulty was not reported in the case study, but the skill needed for this role was confirmed.

Features of the involvement mechanism in the DV case study were:

- Research partners outnumbered researchers (or numbers were more equal) and meetings took place in DV agencies; these arrangements changed the dynamics and power relations to some extent
- The purpose of the meeting was only to engage with research partners and seek their views
- The number of research partners present promoted discussion between them
- The researchers' role in the meetings was predominantly to provide relevant information and facilitate involvement
- Because more than one researcher was present they could support each other to encourage contributions.

The involvement role was more straightforward as a result of the mechanism of involvement. The PPI meetings promoted accessible practice and also required less skilled facilitation because leadership did not require the adjustment of professional meeting norms and the researchers' role emphasised facilitation. However, this mechanism also required a secondary involvement process; feedback from involvement meetings to the TMG and discussion of suggestions made. The PPI meetings supported involvement of a large group of research partners and allocated significant time to involvement, but the organisation and facilitation of two PPI groups and feedback at TMG meetings absorbed a lot of researcher time. Some of the features of these meetings have been identified by others as supporting inclusion, including choosing a non-medical location, having more users than experts present, and facilitation to support service user contributions in particular (Elberse, Caron-Flinterman and Broerse 2010).

Inviting research partners to research management meetings might appear to require less resources than running PPI meetings separately. However, the ethos in the rheumatology department, strong leadership and facilitation, and shared researcher norms underpinned this involvement mechanism and amounted to the accumulated benefit of significant long-term investment in involvement. Given the need to modify professional meetings, in the absence of such supporting factors involvement in research management meetings may be a less robust involvement mechanism. Both mechanisms of involvement in the case studies absorbed significant researcher resources.



Involvement in the rheumatology case study was more embedded in the research process, with research partners positioned as colleagues within the team, than involvement in the DV case study, where research partners attended separate involvement meetings. However, the scale of the research management task in the two case studies was significantly different; in rheumatology the study was small and there were only two team meetings in fourteen months, lasting about four hours. In the DV case study TMG meetings were monthly and lasted three hours. While a significant amount of time at TMG's was spent discussing involvement, the majority of time was focused on other research issues. The decision to organise involvement in PPI groups was therefore more practical and cost-effective given the scale of research management process in the trial. In addition, adapting professional norms to accommodate research partners in a large multi-disciplinary TMG (usually more than 10 people) would have been challenging.

The involvement in research literature has not given much attention to the features of different involvement mechanisms, even though such features are considered important in other domains of involvement (Rowe and Frewer 2005). Therefore, the findings from this project make a contribution to the understanding of the conduct of involvement by identifying the different features of these two involvement mechanisms, with links to the different contexts of involvement. Such findings can help practitioners to make more informed choices about how they conduct involvement and encourage consideration of the potential benefits of different involvement mechanisms.

#### **7.4.4 Resources for involvement**

Resources for involvement were limited in both case studies. However, in the rheumatology case study the involvement co-ordinator was paid for five hours a week to support research partners, maintain a database of contacts and organise training events, and the ethos of the department set norms for researchers which emphasised involvement activities.

In the DV case study the lack of dedicated staff time was a key constraint. Researcher capacity problems undermined involvement activities and plans to develop involvement when other core research responsibilities had to be prioritised, but despite these problems four involvement meetings were supported in a year. Strong researcher relationships with DV agency staff also indirectly supported involvement, but developing and maintaining these relationships also absorbed significant researcher capacity.

The literature recognises that finding time to support involvement can be problematic for researchers, for example, Brett *et al.* (2010) identified eight studies that had reported negative

impacts on researchers related to the time and cost of involvement. Boote, Baird and Beecroft (2010) found involvement in any research activity had cost and time implications, Staniszewska *et al.* (2007) found that involvement in the design of a study took significant time, and Staley (2009) has reported seven studies which identified that involvement required significant time, energy and money. Although it was difficult for researchers in the DV case study to find sufficient time for involvement, this was not described as a negative impact on researchers.

The trial in the DV case study was funded alongside other research studies on DV, and £30,000 was allocated for involvement across all the studies, including funding for staff time during dissemination. The study budget in the rheumatology case was small (under £30,000 in total) and the budget for involvement was described as 'very small indeed'. However, restrictions to involvement due to limited financial resources were not reported in the cases, resource constraints were based on researchers' capacity to devote time to involvement.

In the DV case study incentives for research participants were adapted to pay research partners using shopping vouchers, and travel expenses were also routinely covered, including the use of taxis. Research partners were not paid in the rheumatology case study, although the expert patient participants in phase 1 received vouchers, and while expenses could be paid they were not always claimed. In this case most disagreement was reported on this topic, with different views expressed within researcher and research partner groups not between them. However, there were other rewards for involvement, most obviously including role satisfaction but also including co-authoring articles and attending research conferences.

Payment of research partners was a problematic practical issue, with variation of payment rates and methods within departments, between departments and between institutions in both cases. Discrepancies between guidance and practice on payment were also identified by Evans *et al.* (2014). Despite emphasis on payment for involvement in much good practice guidance (INVOLVE 2010c; Scott 2008; Turner and Beresford 2005) the reality in the case studies was more intractable.

#### **7.4.5 Training**

In the rheumatology case study researchers provided on-the-job training as needed, supplemented by biannual training events to bring research partners together and develop understanding of research more broadly. In the DV case study research partners did not see the need for training or induction for their role which was seen as straightforward. The training event in the rheumatology case study was not attended by either RP1 or RP2, and the training event in the DV case study was not reported as helpful by either of the research

partners who attended because it focused on learning about research, rather than on the research partner role. Although training was provided in both case studies there was no evidence of its benefit.

There was less emphasis on training for research partners in the case studies than is described in the literature, for example, Telford, Boote and Cooper (2004), Brett *et al.* (2010) and Wright *et al.* (2010) emphasise the need for training. Shippee *et al.* (2013) suggest the need for co-learning and training for both research partners and researchers. While in the literature training extends to researchers, in the DV case study none of the researchers had had specific involvement training. Researcher skills in this case were based on hospitality, friendliness and appreciation and qualitative research skills were seen as useful and transferrable. In the rheumatology case study the department provided norms and guidance for researchers and skills were developed in this way, including the skills to facilitate involvement in research management meetings.

#### **7.4.6 Reflection on findings on involvement processes and mechanisms**

Key involvement processes for involvement in research were synthesised in the literature review, and many of the involvement processes identified as important in case studies were also emphasised in the literature. Findings emphasised a friendly and welcoming approach. Two involvement processes that have not previously been stressed were identified, providing recaps and reminders and actively encouraging critical feedback. Findings also confirm the need to provide feedback to research partners about the progress of studies and the impact of involvement as previously identified (Shippee *et al.* 2013; Evans *et al.* 2014). The potential for involvement to have negative effects on research partners was confirmed in both cases, and neither case had specific support mechanisms, although in the rheumatology case the involvement co-ordinator could be a source of support. The complexities of providing support identified in the DV case suggest that the ad hoc approach would benefit from further development.

There was very little reference in the findings of one important involvement process identified in the literature review – the reporting of involvement. However, researchers in the rheumatology case had published a number of articles on involvement, and one research partner had co-authored 22 articles. The chief investigator reflected on the difficulties of including the research partners in the case as co-authors given journal requirements, but she confirmed that their contributions would be acknowledged in publications. In the DV case study the reporting of involvement was not considered during my data collection period.

Differences between involvement mechanisms based on inclusion of research partners in research management meetings and running separate involvement groups have been identified with implications for the facilitation of involvement, where inclusion of research partners in research management meetings was highly dependent on the quality of facilitation and on the modification of professional meeting norms. Separate involvement meetings needed no such adaptation, and the involvement groups in the DV case study had a number of features associated with inclusion as identified by Elberse, Caron-Flinterman and Broerse (2010). The literature oriented to the practice of involvement in research has more focus on involvement processes than on involvement mechanisms, and provides no assessment of the features of different mechanisms. Description of the features of the two different involvement mechanisms used in the case studies contributes to this gap.

The rheumatology department did not pay research partners although expenses were available; this is at odds with Brett *et al.* (2010) who identified payment for time and expenses as a key part of the architecture of involvement, and payment for research partner time was also emphasised recently by Popay and Collins (2014). Payment of research partners was the practical issue where the most divergent views were reported, despite clear guidance this issue remains a divisive and difficult practical problem for involvement. The lack of dedicated staff time was the most significant resource constraint to involvement in the DV case study which was related to researcher capacity issues, this issue has been identified as significant by Staley (2009) and Brett *et al.* (2010). The norms in the rheumatology case study ensured that involvement activities were prioritised, even though there was no dedicated researcher time allocated specifically to involvement, but the work of the involvement co-ordinator was resourced.

The need for training of research partners was not emphasised in the findings, and nor was there evidence that the training provided was of benefit, this contrasts with an emphasis on the need for training in the literature (Telford, Boote and Cooper 2004; Brett *et al.* 2010; Wright *et al.* 2010). These authors also suggest training for researchers, but in the case studies researchers had not had specific involvement training. However, in the rheumatology case study the department's norms of involvement provided guidance on what was expected, and in the DV case study researchers saw qualitative research skills as transferrable.

## **7.5 Context of involvement**

The methodological approach taken in this project with an emphasis on situated knowledge has provided rich information about the context of involvement. Writing up the findings of

this project by case supported the analysis of context and confirms the importance of contextual factors for the conduct of research and involvement. This section provides summaries of the context of involvement for each case study, including the withdrawn case study, and then reflects on these factors in relation to ideas about context identified in the literature.

### **7.5.1 Rheumatology case study**

Rheumatology was described as a patient oriented specialty, and treatment and care included a focus on self-management and coping strategies in the face of a life-long condition with serious disabling effects and ongoing impact on patients' lives. Patient care was delivered by a multi-disciplinary team based in one location, where health professionals had long-term relationships with patients who attended the same clinic for many years. Patients were involved in the development of services, in training doctors and nurses, as well as in research. Involvement in research had developed from prior involvement in provision of care, and researchers were based in offices next to the patient clinic, alongside health professionals.

Clinical and research leadership was integrated, both leaders had been in the department for over 20 years and both emphasised involvement. Involvement across the department had been developed over a long period, and norms included unwritten rules which guided staff selection (see section 5.5.3). The department was described as a place where patients, research partners, health professionals and researchers were all on the same side. Involvement in research was a guiding principle and prioritised in routine research practice; all doctoral students had research partners on their supervision teams.

The context made some aspects of conducting research straightforward, for example senior researchers were also health professionals providing patient care. Therefore, negotiating access to patients for research was simple, and researchers were located next to the patient clinic which also made recruitment, data collection and follow up easy. Patients had long-term conditions and long-term relationships with health professionals, which supported both research participation and the development of involvement relationships. Involvement was embedded as part of normal research practice.

### **7.5.2 Domestic violence case study**

The effects of DV were significant and ongoing for the health and wellbeing of victims and the duration of impact varied depending on a range of social, personal and psychological factors. Service provision was provided by third sector DV agencies, and poor connections between agency and primary care services were identified as impeding provision of appropriate care.

The relationship between DV agencies and researchers was important for the conduct of research, providing research sites and access to potential participants, and building and maintaining these relationships absorbed significant researcher capacity. The DV agencies were also important as service providers, so the agencies were key collaborators in both the conduct and implementation of research, and relationships with agency staff provided researchers with understanding of service provider perspectives on the development and implementation of improved services.

The principal investigator had led the DV research group since 2007 and worked with the psychologist in previous research; both reported commitment to involvement. Prior research had included a significant implementation process, and the trial included a focus on cost-effectiveness of the intervention and dissemination to both policy makers and service providers, with plans for the implementation of positive findings. The research team for the trial was large and researchers met in different groupings as well as in the TMG. There was some history of involvement in DV studies, and in the university department, but there were no shared policies or procedures. The DV research group was growing, and involvement was developing, including building relationships with a third DV agency. In the trial leadership for involvement was provided by the principal investigator, the trial manager and one research associate. Involvement was organised mainly through PPI groups and research partners for the trial also contributed to other studies within the PPI groups, and to other PPI groups. Research partners from different DV agencies did not usually work together, but the development of a more co-ordinated approach was being considered.

The context of research was more complicated in the DV case study; researchers did not provide care to service users and access to potential research participants had to be negotiated with DV agencies. Running the trial in DV agencies required negotiation of acceptable procedures for both researchers and agency staff, and the trial intervention was also a new agency service. While the effects of violence could be long term, service users did not necessarily have long term relationships with DV agencies, and contact details often changed so maintaining contact with research participants was a challenge. The trial was conducted over five years, and required a large multi-disciplinary research team. These factors affected both the conduct of research and involvement because researchers had less connection to service user experiences of violence or their use of services, relative to researchers who were also health professionals in the rheumatology case study.

### **7.5.3 Withdrawn case study**

A summary of contextual reflections from this case study is presented here because it was significant in the development of my thinking about contextual factors. The context was more complex and challenging for involvement than the other two cases, and the understanding derived from these differences contributed to the theoretical development described in section 8.3.2.

The case study was focused on the development of a new involvement initiative in a medical speciality which had little prior involvement, although researchers had experience of involvement in other patient conditions. The research culture was medical and scientific, where treatment episodes were usually short term, so there were not ongoing relationships between health professionals and patients. Treatment was mainly based on surgery and was not oriented to long term impacts on patients' lives. Patients were not a heterogeneous group, and the broader research group within which the case study took place conducted research on a very wide range of health conditions, where patients were very heterogeneous. Although there was a history of involvement in research in some long-term health conditions addressed by the broader research group, there was no history of involvement in research in the specialty at the centre of the case study, and learning from other involvement situations was not easily transferable. Key researchers were not obvious involvement champions, and there was some scepticism about the value of involvement. During the case study significant changes to research infrastructure took place. These changes absorbed spare staff capacity, alongside existing involvement commitments on studies focused on long-term conditions. Involvement plans for a new research infrastructure were then prioritised over plans to develop involvement in the specialty which was the focus of the case study. The context of this case study combined a complex location for involvement where appropriate involvement mechanisms were not easy to identify, little spare capacity, and senior researchers who were not convinced of the value of involvement.

### **7.5.4 Reflection**

This section has summarised important elements of the context of each case study, and identified some aspects which affected both research and involvement. It was evident that the field of research itself – rheumatology and domestic violence – had a significant influence. This factor was first identified by Evans *et al.* (2014), and has been described as the assumptions, procedures and practices that distinguish one field of research from another, including research design. Ennis and Wykes (2013) have also identified aspects of research which had an impact on involvement which included study complexity and study type. Such

features of the research environment had an impact on the cases; the rheumatology case was based in a hospital department where a multi-disciplinary team delivered care to patients over the long term, whereas the DV case was based in the voluntary sector where services were used in a crisis or over the relatively short term, with poor connection to primary care. Running the DV trial in two locations was more complex than developing and testing an outcome measure in the rheumatology case, and the length of the studies was very different.

However, importance of leadership for involvement was common to both case studies. Leadership in the rheumatology case combined research and clinical leadership, and the shared commitment of medical and nursing leads was described as making involvement in research inescapable (see section 5.5.3). Long term leadership had embedded involvement across the department, and included the provision resources for the research partner who coordinated involvement in research. However, in this case study as well as shaping the context of involvement, leadership was identified as crucial in the facilitation of involvement, and as such was also an important process supporting involvement practice. Leadership for involvement in the domestic violence case study was shared between the principal investigator, the trial manager and one research associated, supported by a qualitative researcher.

These findings provide additional evidence that leadership is important for involvement practice. My project confirms that leadership can be considered as both part of the context of involvement as well as a process factor, which was also suggested by Evans *et al.* (2014). Another factor identified as important by Evans *et al.* (2014) was whether or not there was an established culture of involvement. The 20 year history of involvement in the rheumatology case study was connected to cumulative impacts of involvement reported in section 5.3.3, whereas the DV research group was growing and the development of involvement practices to meet their changing needs were being considered by researchers (see section 6.2.5). Such differences were clearly significant.

The influence of context factors on involvement identified in this project reflects the importance that Brett *et al.* (2010) gave to such factors alongside involvement processes for the conceptualisation of involvement. However, the factors that were important in the case studies were related to the research environment, as well to involvement, whereas Brett *et al.* (2010) described context only as whether or not the right conditions for involvement were in place. The importance of the field of research and related research factors confirm that the conceptualisation of contextual factors needs development.



The factors identified in the literature in other involvement domains have more limited connection to the influences identified in the case studies. Abelson's (2001) contextual influences - pre-disposing, enabling and precipitating - identified in health care decision making do not related well to findings. The later development of this model, Abelson *et al.* (2007) with five factors - political, community, organisational, researcher-decision maker relationships, and decision making - do not significantly improve the relevance of this model for the case studies.

Data from the case studies confirm that the context of involvement is important and that it potentially influences both the practice and impact of involvement. The methodological approach taken to the analysis and presentation of findings supported understanding of contextual factors, and some contextual factors identified do reflect findings from other studies. Further reflections on the context of involvement are presented in section 8.3.2, where I have used findings to develop ideas for the conceptualisation of contextual factors for involvement in research.

## **7.6 Representation and legitimacy of those involved**

In both case studies research partners were patients or service users with relevant experiential expertise, involvement was therefore oriented to the 'affected' public (Braun and Schultz 2010) and to a 'public-in-particular' (Michael 2009) where the right to contribute was based on a specific position. There were no problems in identifying the 'right' people to involve in either case study. In the rheumatology case health professionals identified patients who might be interested and passed names to the involvement co-ordinator, and researchers identified new research partners from study participants. In the DV case study DV agency service users had relevant experience, but recruitment was dependent on researcher relationships with agency staff and took more time. Research partner contributions were both normative and technical (for example, drawing on personal experiences and understanding of service provision and use), as suggested by other authors (Dyer 2004; Martin 2008a), and the status of experiential expertise was not contested in the findings.

The legitimacy of research partners was based on first-hand experience from personal and bodily life (Braun and Schultz 2010), and the authenticity of this legitimacy claim was not contested (Michael 2009); no challenges to legitimacy were expressed or observed. Legitimacy of involvement in the case studies was linked to diversity, the desirability of having a range of people involved with relevant and different experiences. In the DV case conducting research on new topics, was seen to require recruitment of research partners with relevant experience.

While researchers in the rheumatology case study described involving people from different educational backgrounds, the group of research partner participants were white, middle class, well educated, and mainly older. Involvement from such groups has been criticised by Church *et al.* (2002), Robinson, Newton and Dawson (2012), and in Pathways through participation (2009). Research partners in the DV case study were more diverse in comparison.

In comparison to the literature case study findings showed little focus on issues of representation, but in the rheumatology case study researchers were clear that research partners were not expected to represent all patients. The reduced prominence of representativeness in involvement which focuses on experiential expertise, as opposed to involvement focused on the general public, has been argued by Martin (2008b), and findings confirm this view. However, Boote, Baird and Beecroft (2010) found that some health researchers were concerned about the representativeness of research partners, as self-selecting, with a high level of interest in the research issue, and different characteristics from potential research participants. However, Hanley *et al.* (2000) suggest that researchers focus on seeking public perspectives, rather than public representatives in involvement in research.

There were two examples of researchers expressing caution about contributions from members of the public involved in patient organisations or campaigning groups, reflecting reports by Braun and Schultz (2010) and (Martin 2008a) about 'partisan' publics, with connection to the desire for the 'ordinary' patient or service user expressed in the literature (Martin 2008a; Learmonth, Martin and Warwick 2009). Caution related to having a specific political agenda and not necessarily being willing to listen to different perspectives. These views reflected researchers' focus on the design and conduct of research as a technical process and related to the substantive rationale for involvement, rather than a site for political expression. This contrasts with the normative rationale where activists are a desirable public which needs to be nurtured, and the literature provides several influential examples to show the potential of such publics to challenge researchers, for example, in AIDS (Epstein 1995) and breast cancer (McCormick *et al.* 2004). There were campaigning patient organisations in rheumatology, and campaigning activities in relation to DV, but research partners in the case studies were not linked to such activities or groups. The choice not to recruit from campaigning groups in the rheumatology case study was reported to preserve a focus on research aims, but this choice also meant that professional power was not challenged by more politicised patients.

Crawford and Rutter (2004) investigated whether the views of members of mental health user groups were representative of 'ordinary' patients, and found that group members' views were

similar to those of randomly selected patients. This challenges the view that members of groups who get involved necessarily differ from 'ordinary' patients. In contrast, Wallcraft and Bryant (2003) found that 38% of mental health service user groups were involved in campaigning. Therefore, evidence that members of user groups are similar to 'ordinary' service users is inconclusive so concerns about activism in involvement are likely to continue.

Researchers in both case studies valued research partners with experience of involvement, but contributions from inexperienced research partners were also desirable. In the rheumatology case experienced research partners were not seen as appropriate for all roles; experienced research partners in this case study also saw the benefit of new partners and different perspectives. No concerns about professionalisation were expressed, so data did not reflect the concerns raised in the literature by Thompson *et al.* (2012) and Ives, Damery and Redwood (2012). However, concern about professionalisation has been reported in other studies, and cancer service users who had been described as professional users, and as 'the usual suspects', found the use of these terms by professionals annoying and divisive (Cotterell *et al.* 2010).

The findings from the case studies show little concern about legitimacy and representation in comparison to concerns expressed in the literature. However, although involvement in health research is often based on the affected public and the legitimacy of experiential expertise, there is also consensus that the diversity of those involved needs improvement (Church *et al.* 2002, Robinson, Newton and Dawson 2012, INVOLVE 2012c). Therefore, there is likely to be benefit in evaluating the diversity of those involved. In addition, involvement in research may not necessarily draw on the affected public, for example, in public health research involvement may need to draw a more general public. Interest groups may also have a legitimate contribution to make in setting the research agenda and identifying research priorities. The allocation of resources to research is of interest to tax payers, and issues related to the development of new medical and scientific technologies are of concern to the general public as well as to affected publics. Carter *et al.* (2013) propose that those with experiential expertise should not be conflated with members of the public in applied health research, and that there are different involvement roles for these groups. Prioritisation of research topics and research questions are more political involvement issues in research and such issues have been addressed using deliberative mechanisms, for example Abma and Broerse (2009) developed a dialogue model for involvement in health research agenda setting. A range of involvement purposes and publics may therefore be applicable to involvement in health research, so drawing on the affected public and experiential expertise, cannot be assumed, even though it is common in involvement in the design, conduct and dissemination of research.

Few conceptualisations of involvement in research address questions about who should be involved. However, Gauvin *et al.* (2010) include six types of publics in their model, and Wright *et al.* (2010) include a focus on diversity and relevance of those involved for research, but neither Brett *et al.* (2010) nor Shippee *et al.* (2013) emphasise consideration of these issues. This is an oversight in need of addressing so that inappropriate assumptions are not made about who should be involved. In section 8.3.3 below I have used research findings to develop some ideas to improve consideration of the appropriate range of experiential expertise for involvement in research.

## **7.7 Power**

The literature review identified a key critique of involvement practice based on the deployment of involvement to sustain existing power relations (Harrison and Mort 1998; Beresford 2002; Martin 2008a) rather than promoting democracy and social justice, and changes to social relations. Two rationales for involvement have been identified and described, a normative rational which emphasises involvement as a means of changing social relations, and a substantive rational which emphasises the importance of outcomes for research, treatments, services and health. This section reflects on power relations in the case studies in relation to these two different rationales, with the awareness that Lukes (1974) described power as an essentially contested concept. Clegg's (1989) ideas have been used to think about different understandings of power in the literature.

In the rheumatology case the researchers' technical and scientific expertise was not challenged, and they were in charge of research. There was no evidence that research partners wanted to control research or make decisions. However, relationships between researchers and research partners were also described as collaborative partnership, and research partners were embedded in the research management process. Power within the rheumatology case study can be understood as a productive use of power (Clegg 1989), where power is not a zero sum game and health professionals and patients can work together for positive benefits. Professional leadership over time (sustained exercise of power) had produced an environment where patients had a strong voice, and a range of impacts of their involvement were identified (see section 5.3) including the identification of new research priorities. While patients were collaborators, the professionals remained in control, and there were limits to patient power (see section 5.7). Nonetheless, patients were active across delivery of treatment and care, in training of doctors and nurses, and in research where research partners were routinely present in research management processes. The head of department identified rheumatology as a patient focused specialty based on multi-disciplinary

teams, where medical dominance was reduced (section 5.5.1), and the sustained involvement of patients over time was associated with changes in relationships between patients and professionals by the consultant nurse (see section 5.3.3).

In this case patients were also seen as powerful allies for the health professionals in negotiations with the hospital authorities, but while one research partner was willing to support the department's interests, another questioned whether patients should do so, because such support was not based on an assessment of what the hospitals' (and patient) priorities should be. These different views describe two circuits of power in health (Clegg 1989). In one circuit departmental interests need to be voiced and support needs to be mobilised, where the hospital is acknowledged as a political system which depends on active participation, including lobbying. The other is evidence-based where knowledge and reason should underpin decisions. The views expressed indicate tension between an evidence-based NHS and the 'real' NHS which has to negotiate interests between health areas with limited resources. The desire for evidence to underpin health decision making relies on 'knowledge' which is something different from 'politics'. In ordinary life such distinctions are common; in social science they are deeply problematic and reflect fundamental problems about the nature of knowledge and its relationship to power.

In the DV case the leading researchers worked actively with DV agencies in research, and were also active in the development of national policy. The trial intervention focused on improving DV care delivered by agency staff, and plans included the potential for a positive trial outcome to be implemented. The DV research group was developing capacity to work across the policy/research/care system which reflected understanding of complex systems of power, where the focus of effort was not just on generating research evidence, but also on building a system where research could be a mechanism for change; this process could be described as the construction of a circuit of power (Clegg 1989).

In both case studies researchers remained in control of research; involvement was not oriented to the transfer of power to research partners but to improving research processes and outcomes. The substantive rationale was not only described by researchers, research partners expressed no desire to be in control of research or to make research decisions. Willingness to get involved signalled an interest in improving services and care combined with a level of trust in, and respect for, researchers' expertise and skill. Such research partner attitudes were underpinned by an acceptance of expert power, not a challenge to it.

In contrast, the normative rationale requires the transfer of power; this is most obvious in the hierarchical theories of involvement based on Arnstein (1969) who describes involvement as a categorical term for power, where the absence of decision making power was also the absence of involvement - the pretence of involvement as tokenism. However, decision making power has been described as a one-dimensional concept of power, which focuses on the exercise of power by agents, ignoring the power of social structures (Clegg 1989). The assumptions underlying the normative rationale and Arnstein's (1969) theory are that the public want power and control, power is a zero-sum game, and therefore for the public to gain power those with it must either share power (in some form of collaboration or partnership) or give it up; at the top of the hierarchy is citizen control where power has changed hands, so user-controlled research is the best kind of research. This conceptualisation of power assumes that agents can change power relations but in health services research structural power is strong, endorsing the primacy of expertise. While there are two newer theories of involvement which draw on different concepts of power (Morrow *et al.* 2010; Gibson, Britten and Lynch 2012) it is not yet clear how these theories will be used and to what benefit. Such theories of involvement may be useful for evaluating involvement oriented to the normative rationale, but they do not address the outcomes of involvement which are central to substantive involvement, so have less relevance for understanding research findings in this project.

The normative rationale for involvement critiques collaboration between research partners and researchers as serving dominant interests, where involvement fails to challenge those in power (Kerr, Cunningham-Burley and Tutton 2007; Weiner 2009; Thompson *et al.* 2012). However, the substantive rationale is based on a different position, where collaboration can serve shared interests to the benefit of research and care. Nonetheless, the capacity for experiential expertise to be of benefit in substantive involvement is also dependent on the expression of different perspectives, which does require involvement to support the expression of difference, as well pursuit of shared interests. While this kind of involvement may marginalise more politicised and adversarial voices, it is not clear that the design, conduct and implementation of health services research is an appropriate location for the expression of more radical and politicised service user and patient interests, given the strength of structural and expert power in this location.

Normative involvement claims the moral high ground, positioning involvement as a mechanism in the struggle for equality and liberation, and the desirable public as the marginalised, excluded and oppressed; however, there is evidence that the public are not necessarily seeking political and decision-making power. Pivik, Rode and Ward (2004) found

that some health consumer organisations surveyed in Canada did not want decision-making power, and Wait and Nolte (2006) reported the public's reluctance to take on the role of rationers of health care. Litva *et al.* (2009) explored the perceptions of different kinds of patient and user groups of involvement in clinical governance policy, and discovered different desired involvement roles. However, their findings demonstrated no desire on any groups' part to achieve control over decision making. Litva *et al.* (2002) and Abelson *et al.* (2004) have identified a public desire for 'accountable' consultation where participants were not seeking decision-making power. Such findings challenge the assumptions underpinning normative involvement and its generic applicability across involvement domains.

## **7.8 Conclusion**

This chapter draws together the findings from the case studies with insights from the literature review in relation to key aspects of involvement. Involvement in the case studies addressed similar tasks to those reported in the literature in other studies on involvement in research. Some authors (Telford, Boote and Cooper 2004; Brett *et al.* 2010; Wright *et al.* 2010; Shippee *et al.* 2013) argue that the involvement role should be clarified for the benefit of both researchers and research partners, however, neither case study provided job descriptions or identified involvement tasks in advance. This was not problematic for research partners, who clearly understood the essence of their role – to contribute to involvement based on their personal experiences – and trusted researchers to seek their input on relevant tasks as appropriate. In the rheumatology case researchers had found that job descriptions could put potential research partners off because the role sounded too difficult, and providing job descriptions might also have the potential to increase professionalisation (Thompson *et al.* 2012) and decrease the diversity of those involved . These findings suggest that it may be most important for researchers to be clear about the involvement role and related tasks.

The involvement role was more complex in the rheumatology case than in the DV case because of two factors. Firstly because research partners participated in research management meetings so their contributions needed good facilitation and adaptation of meeting norms, and secondly because researchers potentially provided treatment and care to research partners, and this dual role required the management of different relationships and establishing boundaries between these roles.

Impacts of involvement were identified in both case studies which were similar to impacts that have been identified in other studies of involvement in research, including impacts on research, on research partners and researchers (Staley 2009; Brett *et al.* 2010; Cotterell *et al.*

2010; Boote, Baird and Beecroft 2010). Few negative impacts of involvement were reported in the case studies, but such potential impacts were identified for research partners. However, involvement did have costs for researchers in terms of their time commitment, and capacity issues for researchers were significant in the DV case study. The project has contributed to the growing evidence base on the impacts of involvement in research.

The need to improve the conceptualisation of impact has been identified. A number of involvement tasks took the form of review processes where researchers presented ideas, documents or plans to research partners for discussion, where the outcome was approval of researchers' proposals. While such processes do not necessarily result in tangible change, I have argued that such processes help to safeguard participants' perspectives and therefore contribute to the quality of research. Some involvement might also lead researchers to abandon ideas or procedures, so involvement could have an impact by stopping things happening too. These issues highlight the need for improved conceptualisations of impact which address such outcomes.

In addition, the rheumatology case identified cumulative impacts of involvement over time and across research domains, and both case studies identified impacts of involvement on research priorities. While linking desired outcomes to the rationale of involvement supports the effective evaluation of involvement, the findings raise the question of how to assess unanticipated benefits of involvement. In the case studies the impacts on research partners could be understood as unanticipated and secondary, because neither case study overtly aimed to produce such impacts. This finding, alongside the contested status of such impacts in the literature (Morrow *et al.* 2010; Ives, Damery and Redwood 2012), indicates that prior clarification of whether or not substantive involvement includes the aim to produce such outcomes is needed to resolve their status. Nonetheless, the unanticipated benefits of involvement were important for, and valued by, both researchers and research partners. The capacity for involvement to deliver substantial unanticipated benefits which has been demonstrated in this project also needs further conceptual consideration to support better evaluation and understanding, alongside the implications of impacts across different domains and over time.

Although the literature review identified different rationales of involvement, in practice in the case studies the purpose of involvement was not problematic, and nor was it the topic of discussion. The tasks addressed demonstrated a strong orientation to the substantive purpose of involvement. This orientation was not imposed by researchers on research partners, it was clear that research partners were motivated to get involved by a desire to improve services,



treatments and care to help others like themselves. Authors aligned with the normative rationale have critiqued such aims as a subversion of the purpose of involvement (Martin 2008a; Beresford 2010; Gibson, Britten and Lynch 2012) and as evidence that involvement was serving established professional interests instead of the interests of the public (Kerr, Cunningham-Burley and Tutton 2007; Weiner 2009; Thompson *et al.* 2012). However, based on the substantive rationale researchers and research partners can share interests and work together in collaborative partnerships for outcomes that are desirable for both.

The evaluation of involvement based on the normative rationale, which values outcomes in relation to improving democracy and social justice, was not applicable to the case studies because they were clearly associated with the substantive rationale and sought outcomes for research. The clarification of rationale provides a strong basis for the evaluation of outcomes, and, given the range of potential aims of involvement, there is no basis for the generic application of particular outcome criteria to involvement practice. The substantive rationale values outcomes in terms of improvements to research, health treatments and care and people's health more broadly (Rowe and Frewer 2000; Harrison, Dowswell and Milewa 2002; Abelson *et al.* 2003; Crawford, Rutter and Thelwall 2003; Wright *et al.* 2010). The status of impacts on research partners may be more central to normative involvement, however, the project has demonstrated that such aims need clarification in relation to substantive involvement. While the case studies had no overt aim to deliver such impacts, other health research projects may include such aims. The project has therefore demonstrated the benefit of linking the impetus in the literature to evaluate the outcomes of involvement (Staley 2009; Brett *et al.* 2010; Staniszewska *et al.* 2011a) with consideration of rationale for involvement, this has the potential to increase understanding of involvement practice and improve evaluation.

Consideration of the impacts of involvement in the rheumatology case also raise a question about the definition of involvement and the distinction between involvement in research and participation in research. One research partner was also a participant in the study; this dual role was not problematic for the research partner or researchers, or from a methodological perspective. While such a situation would be unlikely in many studies it made sense in this situation. However, the contribution was different in each role, so in principle the role of research partner and research participant was still distinct.

In addition, expert patients who were experienced research partners were also chosen as a participant group and their contribution drew on three kinds of experiential expertise:

- Having a relevant health condition.
- Participating in many research studies and therefore filling in many clinical measures.
- Experience of involvement in research.

All three were valuable to the aim of the study. While the formal distinction of role is still intact in the sense that it was clear that contributions counted as data, these participants were selected because they had experience of involvement in research, and their contributions drew directly on such experience. The problem for conceptualising involvement is that the impact of involvement experience is rendered invisible as an impact of involvement by the distinction between participation and involvement, despite the fact that involvement experience contributed to the development of the measure. Given that the development of outcome measures oriented to patient perspectives is an ongoing focus in health services research and an area for increased involvement (Staniszewska *et al.* 2012) this problem might not be a one off 'aberration'.

The acceptability of qualitative research as 'involvement' in trial design has been endorsed in the literature. Staley (2009) reports 'involvement' in the design of a clinical trial based on qualitative research (Donovan *et al.* 2002) as do Edwards *et al.* (2011). Both articles are referred to as 'involvement' in the new impact assessment framework (Popay and Collins 2014), yet both Staley (2009) and Popay and Collins (2014) use the INVOLVE (2013) definition which distinguishes between participation in research and involvement. If this kind of participation can count as involvement, could the contributions of expert patients in the rheumatology case also be counted as involvement? It was clear that the activities described in these articles, whatever they are called, provided access to experiential expertise which improved the design of trials. The problem they share with the contributions of the expert participants in the rheumatology case is whether the improvement is a result of involvement or participation. The contribution of expert patients in the rheumatology presents a stronger argument for consideration as involvement, because they were selected specifically for their involvement experience which was relevant for the study. If doing something called involvement in research is distinctly different from doing something called participation in research, rather than the distinction indicating a formal role and what can be counted as data, the contribution of such expert participants do raise problems for how involvement contributions are classified and evaluated. In my view such contributions should be acknowledged as involvement because they draw directly on involvement experience.

The conduct of this project has identified problems relating to the conceptualisation of both involvement and impact, and highlighted the implications of theoretical problems for the

evaluation of the practice of involvement. The push to evaluate involvement affects both academics in the field and practitioners, and capacity issues for involvement mean that those of us who do research in involvement need to provide practical and effective ways of evaluating involvement, including impacts, without demanding significant extra capacity. While a range of impacts of involvement were identified, concerns about the feasibility of assessing impact (Barber *et al.* 2011) have also been reinforced to some extent. The methodological approach taken in the project emphasised the importance of situated knowledge including a focus on the context of involvement, which supported the identification of cumulative impacts over time. However, the conduct of observations and collection and analysis of documents did not wholly overcome the difficulties of identifying and recording direct evidence of impact. The difficulty of recording impacts was also reported within the rheumatology case study, despite developing a mechanism for the purpose. While the literature strongly promotes the evaluation of the impact of involvement, the feasibility of doing this is therefore still in doubt.

Key involvement processes for involvement in research were synthesised in the literature review which included early involvement; processes that supported good relationships and communication; the provision of training, support and information; resources for involvement and the reporting of involvement. Both case studies included involvement at the design stage, but while involvement was planned across the research cycle there were also gaps in involvement. Involvement processes of importance in the findings reflected most of the areas in the literature review, but there was little reference to the reporting of involvement. Important processes included an emphasis on welcome and appreciation, good facilitation of involvement meetings, and feedback about the progress of studies and the impact of involvement. Two involvement processes which have not been emphasised before were identified; the importance of reminders about studies after gaps in involvement, and the need for researchers to encourage those involved to be critical. Findings did not reflect the emphasis on training in the guidance and literature (Telford, Boote and Cooper 2004; Brett *et al.* 2010; Wright *et al.* 2010), and support was provided on an ad hoc basis by researchers. Although questions about support mechanisms were identified in the DV case, they were not addressed during my data collection period. Involvement was affected by researcher capacity to support involvement in the DV case study, and no researchers had identified time allocated to supporting involvement. However, Evans *et al.* (2014) identified that the formal allocation of time to involvement was not necessarily important if the team have a commitment to it. This was confirmed in the rheumatology case where norms ensured that involvement was

prioritised, and the work of the involvement co-ordinator was also resourced in this case. Payment of research partners was the most contentious practical issue.

The importance of leadership for involvement was clear in both case studies, and this included active facilitation of research management meetings in the rheumatology case, confirming the findings of Evans *et al.* (2014). Involvement in the rheumatology case study was more embedded in the research management process, but the PPI groups in the DV case study were inclusive, involved a large number of research partners and the mechanism modified power relations to some extent. Identifying features of these two different mechanisms contributes to the involvement literature, and may help other researchers to make a more informed choice about how to organise involvement.

The methodological approach taken, and presentation of findings by case study, has provided a rich description of involvement in context and the production of situated knowledge. The case studies highlighted the significance of the context of research for the practice of involvement; the differences between the contexts of the case studies were marked and these factors were key determinants of involvement. Existing conceptualisations of contextual factors did not fit the data well (Abelson *et al.* 2007; Brett *et al.* 2010), but some factors identified specifically in studies focused on involvement in research were more relevant (Ennis and Wykes 2013; Evans *et al.* 2014). Findings confirm that this area is in need of conceptual development. The factors which were identified as important, including factors related to the research environment as well as involvement, have been used to develop thinking in this area. Section 8.3.2 presents this thinking for consideration.

The practice of involvement in the case studies demonstrated little concern with a key issue identified in the literature review; identifying the 'right' people to contribute was not difficult and the legitimacy of research partner contributions was not challenged. All research partners were drawn from the 'affected' public and legitimacy was based on experiential expertise, and on having a range of people involved with different experiences. Some caution was expressed about the involvement those involved in campaigning groups, which echo others' findings (Braun and Schultz 2010; Martin 2008a). In the rheumatology case study those involved were not expected to represent patients more broadly, and experienced research partners were valued but were not necessarily seen as appropriate for all roles. Concerns about the professionalisation of research partners identified in the literature (Thompson *et al.* 2012; Ives, Damery and Redwood 2012) were not therefore reflected in the findings. However, the research partners in the rheumatology case were not diverse. Few theories of involvement in research included specific consideration of who should be involved, and I have developed a

tool to address this oversight, with the aim of encouraging consideration of appropriate experiential expertise and skill for different involvement roles, and to consider the diversity of experience. These ideas are presented in section 8.3.3.

Contributions of research partners to the case studies were both normative and technical (Dyer 2004, Martin 2008a), drawing both on values and experiential expertise, alongside experience of involvement in the rheumatology case study. The association of experiential expertise with the substantive rationale for involvement in the findings suggests that lay knowledge is not the basis for a separate rationale of involvement as some have argued (Beresford 2013). The exercise of power in the case studies was based on assumptions of shared interests and working in partnership where power was not a zero sum game. Researchers were in control and research partners showed no desire to challenge power relations. Expert knowledge was respected by research partners, and technical contributions based on experiential expertise were valued by researchers. Evidence that research partners work in alliance with experts for substantive purposes is described critically in the literature (Kerr, Cunningham-Burley and Tutton 2007; Weiner 2009; Thompson *et al.* 2012), but such critiques are not relevant for substantive involvement, where contributions are made within existing power relations. The lack of desire to make decisions and control research reinforces similar empirical findings (Wait and Nolte 2006; Litva *et al.* 2009) which challenges assumptions in the literature based on the normative rationale that research partners necessarily want decision making power. In the substantive rationale involvement can be aligned with established power relations and authoritative knowledge; this was clear in the case studies and has been reported by others in health services research. Rather than understanding this position as a failure of normative involvement, the findings of the project demonstrate that this approach to involvement is legitimate, and involvement's capacity to deliver substantive impacts of value.

The next chapter presents some theoretical ideas based on the project's findings to address a number of the conceptual problems that have been identified for the evaluation of involvement practice.

## Chapter 8: Theoretical development

### 8.1 Introduction

This project started with the perception of a gap between involvement depicted in guidance and practice, which had also been identified by others, both in involvement in research (Ward *et al.* 2010) and more widely (Delgado, Kjölberg and Wickson 2011). It was understood as stemming from problems with terminology and definitions of involvement which were contested (Boote, Telford and Cooper 2002; Beresford 2007; Stewart 2013). As a result of the literature review it has been understood that problems emerged from more fundamental issues about the meaning of, and rationale for, involvement (Cayton 2004; Dyer 2004; Bochel *et al.* 2008, Forbat, Hubbard and Kearney 2009; Thompson *et al.* 2009; Stewart 2013). Two rationales have been identified and described, the normative rationale and the substantive rationale.

- The normative rationale is oriented to social and political purposes of involvement seeking improvements in democracy and social justice. Desired outcomes relate to:
  - Improvements in the democratic process itself, and to the governance of health provision and care
  - Emancipation and empowerment of members of the public usually excluded or marginalised
  - Improvement in the accountability of research, health care and treatments, and health systems to the public
  - Ensuring that organisations and their decisions are legitimated by the public.
- The substantive rationale is oriented to different outcomes, including improvements in research, better implementation of research evidence, improvements health care and treatments and in health itself.

While different purposes for involvement have been identified, it is not clear whether they are distinct or whether particular involvement initiatives might include objectives related to both rationales. The problem of different purposes and aims for involvement cannot be 'resolved' because they are both legitimate. This means that there is not one legitimate 'theory' of involvement, with significant implications for the understanding and assessment of involvement practice. From the perspective of realist evaluation this could be described as the lack of one more or less coherent programme theory (Pawson and Tilley 1997; Pawson 2013) underpinning involvement as a social intervention, instead there are divergent and potentially

competing theories. As this problem cannot be resolved at the level of theory, this implies that it needs to be considered by those 'doing' it, because only they can legitimately decide what involvement should mean in their situation.

Involvement in the case studies was predominantly associated with the substantive rationale, with limited connection to two more political purposes, but this association was not explicit, it was derived from the involvement tasks conducted. It is not clear whether either researchers or research partners were aware of the range of purposes of involvement identified in the literature.

While people doing involvement are likely to have an implicit theory of involvement, if this is not stated then the basis for evaluation of practice is not clear. As a result of conducting this project I am proposing that the rationale and aims of involvement need to be explicit in order to evaluate the outcomes of involvement more effectively. Therefore, practitioners need a framework to help them to make their assumptions about the purpose of involvement explicit. The purpose of a framework is not therefore to explain what involvement should be for, but to provide a means of clarifying the rationale and aims of researchers and research partners in a specific situation. Such a framework has potential to produce situated understandings of involvement which can be effectively evaluated.

In addition to improving the evaluation of involvement, if rationale is linked to potential involvement tasks and roles this could give practitioners a better understanding of the potential scope of involvement, which could also benefit practice. Making the different purposes of involvement more explicit may also improve research partners' ability to challenge researchers' understandings of involvement. However, findings have shown that providing a job description might put patients and service users off involvement (see section 5.2.6) and work against the desire to increase the diversity of those involved, with the implication that discussion of the purpose of involvement linked to tasks and roles may also be off-putting. This poses a genuine dilemma for involvement in my view, and discussion of the potential scope and role of involvement with potential research partners therefore would need to be handled with care.

However, limited understanding of the potential purposes, role and tasks of involvement in health services research undermines the capacity of both researchers and research partners to evaluate practice and understand the potential benefits of involvement. Many authors agree that improving the conceptualisation of involvement would be of benefit (for example Brett *et*

*al.* 2010; Smith *et al.* 2008; Mockford *et al.* 2012; Staniszewska *et al.* 2011a) and the next section provides a conceptual tool to address this problem.

In subsequent sections of the chapter involvement tasks from the case studies and the literature have been used to develop additional theoretical tools to improve the practice of involvement in health services research. The contextual factors identified in the case studies have been used to develop a new way of thinking about the context of involvement in research, and a tool for thinking about who should be involved in relation to experiential expertise has also been developed.

## 8.2 Framework for the evaluation of involvement

A conceptual framework to support the evaluation of involvement is proposed, presented in Table 16. It builds on realist evaluation which identifies the need to connect context, mechanism and outcomes (Pawson and Tilley 1997; Pawson 2013) and draws on the key components of involvement identified in the literature review.

**Table 16: Framework for the evaluation of involvement**

Components	Evaluation	Power
1. Purposes of involvement and related tasks	4. Evaluation of impact in relation to purposes and tasks identified	7. Evaluation of the constitution of involvement in context. Including consideration of: who decides the purpose and sets the agenda, who makes decisions, and the influence of structural power.
2. Context of involvement	5. Evaluation of the complexity of the context	
3. Mechanisms of involvement including <ul style="list-style-type: none"> <li>• who should be involved</li> <li>• process</li> <li>• mechanism</li> </ul>	6. Evaluation of the appropriateness of those involved; quality of involvement processes, and suitability and fit between purposes, the complexity of the context, and the mechanisms chosen.	

This framework includes all key components including a need to think about and decide upon the purposes of involvement (cell 1) in relation to the context (cells 2 and 5) and then to decide who to involve and how (cells 3 and 6). This theory could guide the statement of a situated theory of involvement that could be evaluated. Consideration of power is included as a separate column because while for the normative rationale changes in power relations would be considered as a purpose of involvement (in cell 1), all purposes of involvement need to consider power in relation in the constitution of involvement, and the contextual influences of structural power which will constrain or enable involvement.



Evaluation of involvement then potentially includes an evaluation of the outcome of involvement in relation to the purposes and tasks identified (cell 4), assessment of the complexity of the context in which it was done (cell 5), assessment of the appropriateness of those involved, the quality of involvement processes and the suitability and fit between purposes, context and mechanisms (cell 6), and an assessment of how power has been exercised to constitute involvement (cell 7).

The benefit of this matrix is that it is relatively simple and provides guidance through processes of planning and evaluating involvement, and it can be addressed at different levels of complexity. It includes a set of components which the literature agrees to be important for involvement, and is potentially applicable across different domains. The different potential purposes of involvement identified in the literature review provide a starting point for thinking about the content of cell 1.

The framework includes consideration of the purpose of involvement which has been identified as problematic (Cayton 2004; Dyer 2004; Bochel *et al.* 2008, Forbat, Hubbard and Kearney 2009; Thompson *et al.* 2009; Stewart 2013). Consideration of who should be involved and appropriate involvement processes and mechanisms, identified as important by Abelson *et al.* (2003), Rowe and Frewer (2005), Martin (2008a and 2008b), Michael (2009) and Braun and Schultz (2010) is also included, as is consideration of how involvement is constituted through different mechanisms and how this affects power relations which has been confirmed as important by Arnstein (1969), Barnes *et al.* (2003), Barnes, Newman and Sullivan (2004), Michael (2009) and Braun and Schultz (2010); alongside the need to consider the context of involvement (Abelson *et al.* 2007; Staley 2009; Brett *et al.* 2010).

While this framework may provide a coherent starting point, there are not yet agreed ways of addressing the evaluation of several of the component parts.

The framework is oriented to those who need to plan, conduct and evaluate involvement activities. It sets out key components that need to be addressed in the planning process, and is therefore better oriented to practice than theories that provide a means of classifying involvement (Charles and DeMaio 1993; Oliver *et al.* 2008; Tritter 2009; Gauvin *et al.* 2010; Robinson, Newton and Dawson 2012; Gibson, Britten and Lynch 2012). While the theories developed by Morrow *et al.* 2010 and Gibson, Britten and Lynch 2012 are helpful in developing thinking about empowerment and emancipation, including consideration of power relations, they do not include all the key issues of importance identified in the literature, in particular they do not address either the purposes of involvement or its impact. While the literature on

public involvement in research provides insight into the processes of involvement (for example, Telford, Boote and Cooper 2004; Brett *et al.* 2010; Shippee *et al.* 2013) these authors do not consider different involvement mechanisms, which is a significant choice for those planning involvement.

Cells 4-7 identify different aspects of involvement for evaluation, and using these ideas consistently might improve capacity to compare evaluations of involvement. While the feasibility of evaluating many aspects of the impact of involvement in health research have not yet been established (Barber *et al.* 2011), the linking of evaluation of impact to the identification of purposes of involvement may improve feasibility because a better understanding of purposes (and tasks) is likely to support evaluation of impact. For example, if the purpose of involvement included benefits to research partners, impacts on research partners would be considered as impacts of involvement.

The content of cells would need to be developed and modified to suit different domains and contexts for involvement, but this flexibility is based on a coherent structure rooted in important concepts identified in the literature. The framework for evaluating involvement provides a new and original way of conceptualising involvement. The next section of this chapter presents ideas that focus on the development of ideas specifically for public involvement in health services research and provide tools to improve consideration of cells 2, 3 and 5 specifically for this context.

### **8.3 Towards a theory of involvement in health services research**

This section presents ideas that contribute to the development of ideas for involvement in health services research. The first section links the purposes of involvement to involvement tasks, which include the tasks identified in the case studies and other involvement tasks identified in the literature. The second section develops thinking about contextual factors, and the third section provides ideas to clarify who should be involved.

#### **8.3.1 Linking purpose to role and tasks.**

Different involvement purposes need to be linked to involvement tasks to make them of most practical benefit for both planning and evaluation. The purpose of identifying potential tasks and aims for the role in health services research is to synthesise current knowledge and present it in an accessible way, it is not to provide a normative framework against which involvement should be judged. All tasks will not be addressed in all research studies. Table 17 below should, therefore, not be mistaken for an attempt to dictate what should be done; it provides ideas for consideration by others to help them develop their own plans.

The tasks and roles I have listed in the table are not only tasks for involvement or for research partners; some of them are also key tasks and concerns of researchers, health professionals and others. Such tasks are in the table because the data and relevant literature suggest that research partners can contribute to them. Table 17 should be seen as work in progress; if it is judged to be potentially useful it will need refinement.

The range of tasks listed in the table has been developed based on this project so they are oriented to the substantive rationale. Therefore, the table does not include benefits for research partners, because the impacts on research partners reported in the case studies were not the result of an aim to produce such impacts. However, if the purpose of involvement was to empower, or otherwise benefit research partners, then this task should be included. In this way the purposes of involvement should inform the development of involvement tasks and roles.

**Table 17: Potential involvement tasks in health services research (part 1)**

Stage of research	Potential aims	Potential tasks
Research design and planning	To make sure the right research is being done	Prioritisation of research topics which are important for affected public.
	To make sure research will benefit affected public.	Research questions address issues of importance.
		Research will generate knowledge that could improve health, treatment or care.
		Research is measuring and/or valuing things in findings and results that are important.
	To make sure research is acceptable for potential participants	Research methods are reasonable, ethical and practical.
		Treatments, procedures, surgery and other interventions or care given or withheld are reasonable and ethical.
		Risks and/or benefits to participants are reasonable, ethical and communicated clearly.
	To make sure researchers communicate well with potential participants and participants.	Plain English summary, patient information and research instruments are easy to read, accessible and easy to fill in.
To help researchers secure funding and get approval for research.	Letters of support and endorsement of researcher plans.	
To make sure there are good plans for involvement.	Involvement plans for conduct of research and dissemination of findings are robust, clear and resourced appropriately.	

**Table 17: Potential involvement tasks in health services research (part 2)**

Stage of research	Potential aims	Potential tasks
Conduct of research	To make sure research is acceptable for potential participants.	Treatments, procedures or interventions given or withheld are timely and delivered with sensitivity.
		Benefits and risks for participants are reasonable and acceptable.
	To make sure researchers communicate well with potential participants and participants.	Information provision and collection is appropriate and timely.
		Verbal communication in recruitment and data collection is clear, using simple words and language. Advising on and piloting such processes.
		Documents are clear, of appropriate length, and easy to read and fill in.
	To support recruitment and retention	Consideration of where, when, who and how to approach potential participants.
		How best to keep in touch, advise on retention strategies.
	To support data collection	When and where to collect data.
		Pilot interviews and questionnaire completion – considering question order, clarity, time taken, and other practicalities.
		Collection of data in some studies.
To support data analysis	Providing patient, service user, carer perspectives on qualitative coding, themes, and/or appropriate names of themes.	
	Conduct data analysis alongside researchers in some studies.	
Dissemination	To identify findings of interest to patients, service users and/or carers.	Review range of findings to identify those of most interest/benefit.
	To encourage communication of research findings to non-academic audiences.	Advise on communication of study findings to participants.
		Advise on communication of study findings to patient and service user/carer groups and organisations and to health professionals.
	To contribute to academic reporting of research and findings.	Feedback and/or co-writing of journal articles and research reports.
	To help to present/share findings.	Attend conferences, events and meetings to support dissemination.
	To encourage implementation of research findings.	Encourage researchers to consider how research findings might change treatment and care.
To encourage reporting of involvement.	Acknowledgement of contributions in publications. Active contribution to publications reporting involvement processes and impact of involvement.	

Some elements of the involvement role described in Table 17, particularly the assessment of research priorities in relation to patient/service user need, making sure that research measures the right things and results in changes to health or care, are difficult tasks for research partners (and others) to address. I have put these challenging tasks in the table

because the literature assumes that patients and service users can make a contribution to these issues. If that is so, the ambition should be communicated to researchers and research partners, so they have more chance to look for ways in which they might be addressed. However, introductory information would need to make it clear that some of the tasks are known to be difficult to address for researchers as well as research partners.

Setting the research agenda and prioritisation of research topics takes place in a number of locations in health, including at the policy level and in the commissioning and funding of research. However, deciding research priorities also takes place at the start of the research design process and the case studies resulted in the identification of additional research priorities, so this task is included. Abma and Broerse (2009) describe case studies where patients participated in setting the agenda for health research, and their dialogue model linked this process to the conduct of research. Both Staley (2009) and Brett *et al.* (2010) describe reports in the literature where involvement in research has identified topics for research and shaped the research agenda.

The other tasks described in Table 17 are drawn from the case study data, and are reported in reviews of involvement in research, including Smith *et al.* (2008), Staley (2009), Brett *et al.* (2010) and Boote, Baird and Cooper (2010). While Staley (2009) and Brett *et al.* (2010) identify and describe impacts of involvement in health research across different stages of the research cycle, identifying and presenting potential involvement tasks in a tabular form provides easier access to this information in a synthesised form. Sources providing examples of tasks and their impact on research could be linked to cells of the table, to provide more detailed information if required. While the content of the table could be extended to include additional tasks from the literature, a balance needs to be maintained between the number of tasks and the length of the table. Shippee *et al.* (2013) identify three phases and eight stages of research as locations for involvement in research. However, although the benefit of involvement at each stage is described, their framework does not describe involvement tasks which undermines its practical utility. Their message that involvement can take place right across the research process does little to support understanding of the potential for involvement without reviewing the more detailed accounts of involvement which underpinned the framework.

Many of the theories oriented to the practice of involvement in research suggest that the involvement role should be clarified including Telford, Boote, and Cooper (2004), Brett *et al.* (2010); Wright *et al.* (2010); Shippee *et al.* (2013), but the literature does not provide tools to do this. Table 17 provides a new and accessible way of synthesising and presenting information about involvement tasks and roles for consideration by researchers and research

partners, thus improving the identification of relevant involvement tasks for specific situations. Further research is needed to develop the content of the table and test its practical utility to health researchers and research partners.

### **8.3.2 Context factors**

The development of ideas presented in this section is based on a need to better understand and distinguish different kinds of context factors. I have used the concepts of macro, meso and micro levels to distinguish different ideas about the context in relation to their distance from the practice of involvement.

A hierarchy of contextual factors is proposed with three levels, with two of the factors having subordinate parts. In the following sections the links between these factors and the data are described.

1. Macro level: epistemological location and government policy.
2. Meso level: Research factors.
  - a. Field of research
  - b. Proximity or distance
  - c. Patient/service user
3. Micro level: Involvement factors.
  - a. Leadership
  - b. History of involvement
  - c. Provision of learning and development opportunities.
  - d. Institutional policies.

#### ***Macro level: Epistemological location and government policy***

Involvement in health research is located in a process of knowledge production; however, there are many kinds of health research which draw on different epistemologies. In the case studies (and much other health research funded by the NIHR), research was oriented towards the production of generalisable knowledge about treatments, services and care, intended to serve large populations of patients and service users. This location is often described as health services research, and while it includes many methodological approaches, it has a strong orientation to quantitative methods and population health. This epistemological location is based on technical expertise and the production of relatively 'strong' truth, for example by conducting randomised controlled trials valued for producing high quality evidence. This kind of research is the domain of expertise and involvement brings research partners and their experiential expertise into expert knowledge production processes.

I propose that thinking about involvement in health research should be based on epistemological locations, such as health services research, distinguished from other kinds of research, for example, participatory action research. This distinction is important because in health services research many values and norms are not negotiable; they are embedded at a system level, and reproduced in research commissioning and funding processes and orientation to evidence based medicine. In making this distinction I do not intend to devalue other epistemological locations, but suggest that involvement in such locations needs to be theorised differently. As with many other distinctions in involvement while health services research does describe a location, it does not have a clear boundary which may raise some difficulties.

An associated contextual factor which acts at a macro level is the policy context within which health services research takes place. In the UK currently this context includes substantial support for public involvement in health research, including involvement in the funding and commissioning of research, setting research priorities, conducting research and dissemination of findings as described by Staniszewska (2009) and Evans (2013). These policy imperatives propel health researchers into involvement activities, whatever their attitudes and understanding of its potential. Both these macro level factors shape the broad context of involvement in health services research.

### ***Meso level: Research factors***

The next layer of context factors are research factors because they relate to the research environment within which involvement take place. In the case studies these factors had a significant enabling and/or constraining impact on involvement.

### **Field of research**

This factor was first identified by (Evans *et al.* 2014) and I contributed to the development of the idea in this study. Components of the field of research are:

- 1. Health topic, because involvement will vary depending on the health topic, and become more complex if a bigger range of topics are covered.**

In the rheumatology case study research addressed a group of closely related topics, whereas research in the withdrawn case study was focused on a much broader range of health topics.

**2. The range of academic, medical and scientific disciplines being drawn on in research.**

In the DV case there were researchers with more diverse academic and medical/clinical backgrounds. The context of research becomes more complex where studies draw on more diverse disciplines.

**3. Complexity of knowledge base and level of understanding needed by research partners.**

In the rheumatology case study development of an outcome measure required some technical understanding on the part of the expert patients who took part, but the study was focused on treatment outcomes that were of importance to patients. In the DV case the research addressed an issue of importance to the service users involved, and while the trial methodology was complex, and the clinical and psychological expertise underpinning the intervention drew on expert knowledge, research partners did not need technical knowledge to contribute within the PPI groups. Therefore, this environmental factor combines the complexity of the knowledge base being addressed by research, and the extent to which research partners need to understand it in order to make a contribution.

**4. Research design, study type and complexity.**

The DV case study was a trial, and the size, scale and length of the research determined the complexity of research management processes. Given this design it made more sense, and was more cost effective, to involve research partners in PPI groups, so the design had implications for involvement. The research design was also identified as important by (Evans *et al.* 2014). Ennis and Wykes (2013) identified some additional factors in a study assessing the impact of involvement on studies on the Mental Health Research Network portfolio. Factors they identified included study type (observational/ interventional/or both), and study complexity which included a number of issues (frequency of assessments, number of study sites, and number of follow up contacts). These issues affect the context of research and therefore involvement.

**5. Funding body.**

Ennis and Wykes (2013) also identified that the research funder made a difference to involvement outcomes, so I have included the funder as another factor under the heading field of research.



While the first two factors in this list will make a difference to research and involvement, they are complex factors which could be described but would be difficult to measure. However, it might be possible to develop rating scales for the last three elements of this factor. If this were possible it would enable researchers to rate the field of research for complexity, providing some basis for comparison of the contexts of different health services research studies.

### **Proximity or distance**

There were a number of influences in the case studies that suggested ideas of proximity or distance. I have identified four elements:

- 1. Proximity or distance between research questions and issues of importance to patients, service users and carers.**

In both the rheumatology and DV cases the research questions were close to issues of importance for patients and service users. Where there is close proximity, involvement is likely to require less training and support to understand the research, and research partners may also be easier to recruit.

- 2. Proximity or distance between researchers and potential study participants.**

In the rheumatology case researchers were located next door to a clinical service from which many study participants were recruited, but in the DV case both research sites were distant from research offices. Physical proximity made a difference to recruitment in both cases.

In addition, in the rheumatology case researchers had easy access to participants because leading researchers in the department were also clinical leads, so links to potential research participants and the health professionals working with them were straightforward. In the DV case, there was more distance between researchers and potential participants, and researchers needed to work with third sector agencies and staff to recruit participants.

These issues are important because recruitment and retention of participants is an important focus of involvement, so factors that affect recruitment and retention also affect the involvement role. In addition, because the rheumatology case had close proximity (of both kinds) to potential study participants researchers needed little advice from research partners on recruitment, but in the DV case researchers needed

support and advice both from agency staff and research partners on recruitment and retention issues.

**3. Proximity or distance between researcher discipline and service provider staff discipline.**

Another kind of distance had to be negotiated in the DV case study, the lead researchers were a GP and a psychologist, but the services from which study participants were to be recruited were delivered by third sector agency staff. The integration of research and clinical leadership in rheumatology diminished this distance. Where there is a bigger discipline 'gap' researchers are likely to need more advice and support to conduct research.

Again, these factors might be developed into a rating scale to support assessment of the complexity of the context for involvement.

**Patient/service user**

The third research context factor identified is a patient/service user factor. This has four component parts:

**1. How seriously a health condition affects the people who are the subject of research, and how ill study participants are.**

Thompson (2007) identified factors that affected patients' desire for involvement in treatment decision making, and acute and serious illness reduced demand. Such factors also affect recruitment of participants into research, and therefore have implications for involvement in research. In addition, involvement of research partners with more serious health conditions will require more consideration and adjustment of research processes.

**2. Short or long-term impact of a health condition.**

Rheumatoid arthritis is a life-long condition, and DV could be either a relatively short term problem for some or a longer-term problem for others. In the excluded case study some conditions only had short term impacts on patients. Where health conditions have long term impacts on people and their lives the need for involvement is stronger, whereas if medicine can resolve a health problem involvement is more related to short-term treatment processes. Doing research where impacts are shorter term is likely to be more challenging.

**3. Short or long-term need for treatment and care, and whether it is provided by the same or different services and health professionals over time.**

In rheumatology some patients had attended the same hospital clinic for many years, and there was continuity of care and ongoing relationships between patients and health professionals. In DV women were more likely to access services during a crisis, and while they might live in a refuge for some time and get to know agency staff, such relationships were shorter-term than clinical relationships in rheumatology. This factor will affect the conduct of research and therefore of involvement.

**4. Third sector organisations and patient or service user groups associated with a health condition; including the number of organisations, strength, and range of activities.**

This would include consideration of whether groups focused on campaigning, providing information and support, or funding research. In rheumatology there were a number of patient groups and organisations, and many DV agencies were located in the third sector, but there were no known patient organisations relating to the medical specialty at the centre of the excluded case study. This component could include the extent to which a health condition is characterised by patient or service user activism and campaigning in relation to controversial issues, for example, mental health has a strong service user movement and activism which challenges conventional approaches to treatment and care (Rose 2014). Consideration of this aspect of the context draws in consideration of the broader social and political issues associated with different health conditions.

Such factors influenced the research in my case studies and some of these factors have been reported in the literature, for example, involvement has traditionally been developed in relation to serious health conditions with a long term impact, where there are third sector organisations or patient/service user groups. Boote, Wong and Booth (2012) reviewed literature published on involvement in health research between 1995 and 2009. The most common health topic area was mental health, and of the eleven health topics specified five included long term conditions (mental health, cancer, diabetes, stroke and learning disabilities). The other five health topic areas specified were: health of black and minority ethnic communities and indigenous groups, children and parenting, drug and alcohol addiction, older people, and the health of vulnerable groups, all of which also are areas where there are many user oriented organisations.

These factors had a strong impact on the conduct of research in my case studies and therefore on involvement. Many of the challenges for involvement in the excluded case study were the result of complex research factors, whereas the context of the rheumatology case study benefitted from very close proximity, and had patients with long term conditions who had long term relationships with the same clinical service. In the DV case study researchers had developed strategies to address their research environment, most obviously working DV agencies. While these factors may need modification and development they provide a basis on which to develop thinking about the complexity of research environments and its effects on involvement, and have the potential to be developed into rating scales which would provide a means of comparing the complexity of different contexts for involvement in research.

### ***Micro level: Involvement factors***

The next layer of context factors are involvement factors because they relate to the involvement environment. These include contextual factors identified by Brett *et al.* (2010), because they were described as affecting the atmosphere and attitude within which involvement was conducted.

There were two factors identified which affected involvement in the case studies, leadership and whether or not there was a history of involvement. Alongside these two factors, I have identified two others that were not important in the case studies, but which might be relevant. They are the availability of learning and development opportunities for researchers and/or research partners within a local or regional area, and the influence of institutional involvement policies. I have included these two issues here because they could either enable or constrain involvement.

### **Leadership**

It was clear in both case studies that leadership from senior research staff had a significant impact. In the rheumatology case study sustained commitment to involvement over time by the head of department and consultant nurse had created a strong ethos of involvement which had become embedded in research and clinical practice. This context factor was also identified as significant by Evans *et al.* (2014) but had not previously been identified. While this is an important context factor, research leadership may be a given in specific situations, and personal characteristics and values may be either enabling or constraining factors. However, understanding the significance of leadership can help motivated researchers to develop involvement, for example, by increasing understanding of the importance of

facilitation and adaptation of meeting norms when research partners are involved in research management meetings.

### **History of involvement**

In the rheumatology case study there was a significant history of involvement which had been developed over a 20 year history of medical/nursing/research leadership and involvement was embedded in the department. At the other end of the spectrum the withdrawn case study had no history of involvement in the medical specialty at the centre of the case, although researchers did have experience of involvement in some related health topics focused on long term health conditions. However, the more complex research factors made transferring learning between health topics difficult. The importance of the history of involvement was also identified by Evans *et al.* (2014).

However, understanding that the history of involvement is important does not help to develop plans for involvement in the short term. It is also unlikely that some features of the rheumatology case study, for example integrated and sustained clinical and research leadership over 20 years, could necessarily be reproduced in other situations, however desirable they might be. Nonetheless, researchers with a commitment to develop involvement could benefit from understanding more about such factors, which could support the long term development of involvement with associated benefits.

The development of the context factors presented in this section is a contribution to the conceptualisation of involvement in research. These factors need to be considered in relation to a broader range of health research, tested and developed further, but they have the potential to improve consideration of the context of health research for involvement.

### **8.3.3 Who should be involved**

An important theme identified in the literature focused on questions about who should be involved, and questions of legitimacy, representation and diversity. Table 18 provides some ideas to guide the selection of people with appropriate experiential expertise for specific involvement situations. In the case studies, the focus was on the affected public and experiential expertise. However, public health research might be oriented to a more general public, and therefore need a different approach to identifying the 'right' people. It is also potentially important to consider different interests; Martin (2008a) differentiated between the interests of service users, carers, citizens, interest groups, and tax payers who might have overlapping but distinct interests and involvement roles, and argued that the convergence of interests in involvement should not be assumed.

However, my focus is on the affected public and the range of potential sources of such expertise. More systematic consideration of who should be involved could improve the recruitment of research partners for a specific role, and promote more diversity of involvement. Table 18 provides six potential sources of expertise.

**Table 18: Sources of expertise**

<b>Experiential expertise</b>	1. Having a health or life 'problem'	2. Using health or social care services or having particular treatments	3. Having a distinct perspective – social location
<b>Other sources of expertise</b>	4. Experience of involvement in research	5. Experience of doing research	6. 'Other' life experience

Cells 1 and 2 in are the most obvious sources of experiential expertise, and are likely to be the most important focus when considering who needs to be involved in research. The research partner expertise drawn on in both case studies was based on cells 1 and 2. However, cell 3 is an important source of experiential expertise for some research studies, for example, those which focus on access to treatments and care for specific groups of the population, and provides a way of considering the diversity of those involved.

The cells in the second row reflect other sources of experience that might be needed in some involvement roles. Five of the research partners in the rheumatology case study had significant experienced based on cell 4. The need for research skills to collect and analyse data were not demonstrated in the case studies, but researchers in rheumatology had involved research partners in qualitative analysis in other studies. The literature reports that some research partners do conduct research tasks requiring cell 5 skills, for example to collect data in interviews (Faulkner 2006; Wright *et al.* 2006). Cell 6 in Table 18 acknowledges that research partners bring other life experiences to involvement roles, which at times might be beneficial.

While the experiential expertise in cells 1, 2 and 3 are agreed as a basis for involvement of the affected public, the expertise in cells 4, 5 and 6 are controversial as the basis of more professionalised involvement, which has been criticised by Thompson *et al.* (2012) and Ives, Damery and Redwood (2012). However, researchers in the case studies supported the involvement of experienced research partners, although they were not seen as appropriate for all roles. Thompson *et al.* (2012) reported that some research partners involved in cancer research drew on expertise from prior professional roles in involvement, such expertise would

be located in cell 6. Theories geared to the practice of involvement in research have not generally focused on who should be involved, and while Wright *et al.* (2010) and Gibson, Britten and Lynch (2012) do suggest inclusion of a diverse group of research partners, they do not provide tools to support this process.

Evaluation of who was involved could be addressed by considering the appropriateness and diversity of those involved in relation to the cells in Table 18, considering whether the range of research partner expertise was appropriate for the involvement purposes and role. The evaluation of who had been involved is only explicitly suggested by Wright *et al.* (2010); it is not included in the impact assessment framework developed by Popay and Collins (2014).

Improving the consideration of the range of experiential expertise which might be needed by the affected public has the potential to improve the planning and practice of involvement and increase the diversity of those involved. I have provided a new conceptual tool to support this process.

## **8.4 Conclusion**

In this chapter I have developed a range of conceptual tools to support the planning, practice and evaluation of involvement. The framework for evaluation of involvement potentially has wide applicability; it provides a coherent structure can be used in different domains. It is rooted in key concepts identified as important within the involvement literature, for example, Martin (2012 p. 1852) argues that *'doing justice to public participation demands careful consideration that matches rationales, publics and processes'*, and Lehoux, Daudelin and Abelson (2012) agree with the need for these three key components to be articulated as clearly as possible. The addition of consideration of the context of involvement is supported by Abelson *et al.* (2007) in the wider literature and by Staley (2009) and Brett *et al.* (2010) in involvement in research, as well as in realist evaluation (Pawson and Tilley 1997, Pawson 2013). Linking the evaluation of the impact of involvement to the purposes of involvement has the potential to improve the feasibility of impact assessment, which can be addressed at different levels of complexity. As well as evaluation of impact in relation to purpose, the theory directs attention to the need to evaluate the complexity of involvement contexts, and appropriateness of who is involved, the quality of involvement processes and the suitability and fit between purposes of involvement, complexity of the context, and the mechanisms chosen. Involvement mechanisms, together with the processes of involvement, shape the scope of involvement including the exercise of power. The framework for evaluation of involvement therefore brings together key concepts of involvement in a new and original form.

In section 8.3 I have specifically addressed involvement in health services research, and developed tools with potential to improve the evaluation, planning and practice of involvement. The linking of purposes of involvement to involvement tasks and roles starts to put flesh on the bones of the framework for evaluating involvement in this domain. Table 17 provides a new way of presenting potential involvement tasks and roles which is accessible to researchers and research partners, with the potential to increase understanding of the scope of the involvement role. The benefits of doing this needs to be weighed against the potential for such a tool to demotivate and put off less experienced researchers or research partners because of the scale of the potential task.

The data in this project has been used to develop a new and original conceptualisation of context factors in involvement in research, based on epistemological location and policy at the macro level, research factors at the meso level, and involvement factors at the micro level. I have also developed a new conceptualisation of different forms of expertise which can support consideration of the appropriateness and diversity of experiential experience needed for involvement roles.

The theories developed based on this project make a contribution to the identified need to develop the conceptualisation of involvement in the field.



## **Chapter 9: Conclusion**

The concluding chapter summarises the contribution this thesis makes to the field of involvement in health research. I also reflect on the conduct of my project and its strengths and weaknesses, including the contribution of my Advisory Group.

### **9.1 Contribution to the field of involvement in health research**

This thesis contributes to the field of involvement in health research in a number of ways. The literature review provides an understanding of key critiques of involvement practice and their connection to different underpinning rationales. The normative and substantive rationales have been shown to value different kinds of outcomes with significant implications for the conceptualisation and evaluation of involvement. I have demonstrated that the criteria for evaluation need to be clearly linked to rationale, aims and tasks to improve understanding of whether, and to what extent, the practice of involvement delivers on desired objectives. Addressing the evaluation of involvement in this way has potential to increase the connection between theory and practice.

In addition to considering the purposes and outcomes of involvement, the literature review synthesised five key process factors important for the conduct of involvement. While the context of involvement is agreed as important, existing conceptualisations of contextual factors were limited and in need of development. A number of key components of involvement were distilled in the literature review, and I propose that all these components potentially warrant attention in the evaluation of involvement practice. Current models of involvement in research were reviewed in relation to these components, and while existing theories provide different ways of conceptualising involvement, they do not address all the key components. I have used the key components to develop a framework for the evaluation of involvement. These findings are important for both the conceptualisation and practice of involvement in health services research, and are a new contribution to knowledge.

The thesis has provided a rich picture of involvement in context in two case studies. Analysing data from both inductive and deductive perspectives, and presentation of findings by case supported the understanding of different aspects of involvement in relation to the setting in which they were produced, and provide a more holistic account of involvement. The involvement role and tasks identified in the findings reflect a similar range of tasks found in other studies. Two processes of involvement that have not previously been emphasised were identified (the need for recaps about research and active encouragement to be critical), and

the findings provide understanding of the features of two involvement mechanisms. This consideration of involvement mechanisms fills a gap in the literature on involvement in research with potential to help practitioners think about how best to organise involvement. The impacts of involvement identified in the case studies contribute to the evidence base, and consideration of impact in relation to rationale identified a range of conceptual issues related to outcomes. In particular, the potential for involvement to deliver significant unanticipated impacts raises problems for understanding the status of different kinds of impacts. The need to clarify whether involvement aims to have an impact on research partners and researchers has been demonstrated as of particular importance for the evaluation of substantive involvement. Power relations in the case studies were understood as based on assumptions of shared interests and partnerships working, and I show that such collaborative involvement, based on the capacity of research partners with experiential expertise to make both technical and normative contributions, is a legitimate approach to involvement focused on improving research, treatments, care and health.

I have produced a framework for the evaluation of involvement. It is accessible and focuses attention on the key components of involvement with potential to support better planning and evaluation. Alongside the framework I have developed ideas that contribute to a theory of involvement in health services research, with the understanding that social science expertise needs to be translated and applied by others, so that knowledge can be used by non-experts in the field. Providing accessible theories improves the potential for conceptual developments to improve the way that involvement is planned and conducted. With refinement and testing, the tools I have developed have potential benefit for the understanding and evaluation of involvement in health research.

My thesis represents an answer to my research question; I now understand more about what is going on in my field and the thesis communicates this understanding. I intend to test out the ideas presented in chapter eight in further research. Applicability to practice is the key test because the project was oriented to the production of theory that can make a difference to practice. As such this thesis is a critique of existing conceptualisations of involvement, not because they are not useful, but because they are often inaccessible to non-specialists who might make use of them. The communication of the findings of health research to the public is stressed in the involvement literature; it is just as important that the findings of research on involvement are made accessible to health researchers, research partners and other stakeholders.

## 9.2 Conduct of the project

The methodological approach I took based on realism, abduction and theoretical reflexivity fitted the project well; this can be seen in the way that the framework for the evaluation of involvement is also a development of realist evaluation. The approach also supported the production of situated knowledge, and the combination of data driven and theory driven analysis enabled the development of a nuanced understanding of involvement practice linked to the conceptualisation of involvement. Collection of data by interview, observation and documentary analysis reduced reliance on accounts of involvement to some extent, particularly in the DV case study where there were more opportunities for observation. Data analysis provided insights into the connections between the aims of involvement expressed in involvement tasks, processes and mechanisms of involvement, context, and outcomes. My approach to data analysis supported the creative development of conceptual thinking, and presentation of data by case was particularly helpful in producing understanding of the context of involvement, which was been identified as an important area for development.

However, while the methodological approach had many benefits, it also resulted in the withdrawal of one case study at the end of the PhD. The presentation of data by case raised problems in relation to confidentiality, with implications for the presentation of sensitive findings. The withdrawal of consent by one key participant had a range of implications which meant that it was not possible to only withdraw individual data. While the potential for qualitative research of this kind to produce situated knowledge is clear, my project highlights the risk of taking this approach, and the difficulty of using it to present significant critical insights. This learning can be used to improve the negotiation of future case studies, and has developed my understanding of the complexity of ethical issues in the conduct of this kind of qualitative research.

The qualitative approach enabled a focus on different perspectives and understandings; while I was looking for variations in the perceptions of involvement in the case studies between researchers and research partners I did not identify any significant variations. The combination of data collection methods provided some opportunity to compare information from different sources, for example, the descriptions of involvement in research bids with what had been done. The power of such methods would be improved if I had been conducting an inquiry throughout the full research cycle, from the inception of ideas to dissemination.

Opportunities to conduct observations in my case studies were more limited than I imagined in my research design which was too ambitious. The limited opportunities for observation in the

rheumatology case study were a concern, but researcher and research partner interview accounts reflected shared perspectives, and the one area of disagreement in the case study (about payment of research partners) was not disagreement between these groups but across both groups. These features of the interview accounts increase my confidence in the account of involvement presented.

My methodological position located me as inevitably affecting the social world I studied, and taking up the role of participant-observer in the DV case study had an effect on involvement activities. As a participant observer I gained a deeper understanding of involvement activities and contextual contingencies, and while this choice increased my impact on involvement activities and on the data generated, the increased understanding gained outweighed this researcher effect.

Although I conducted fewer interviews than I intended in my research design, nonetheless the accounts of involvement I collected were rich and a key source of data for this project. I collected many documents in the project, and they were not a rich source of data. Nonetheless, they provided important contextual information and enabled the comparison of how involvement was described in research bids and governance documents with the reality of involvement practice.

### **9.2.1 Involvement in my project**

I met with my Advisory Group for my project three times while I conducted this project, and a final meeting is planned. There were also a number of informal contacts with members of the group in relation to specific issues. My colleagues provided helpful feedback on several issues during the project, including reading and commenting on a long draft analysis of one case study. I very much appreciated their support and encouragement; however, they contributed on an occasional basis and most of the decisions about my work were made by me in consultation with my supervisors, so their impact on this work was limited because I sought their advice in a limited way.

## **9.3 Final words**

Doing this project was in part a journey towards understanding the question I had asked, as well as understanding how to answer it. In retrospect my broad question was the right one, because it allowed sufficient space for the inquiry to emerge. My prior experience of involvement was a key resource and grounding for the work, it helped me to navigate a challenging research process, and kept me oriented to the gap between theory and practice.

My desire at the start of this project was to make more sense of my experiences of involvement and to find ways to make a more helpful contribution when I provide advice and guidance on involvement to others. I have achieved these aims in this project, and my work already informs the work I now do in involvement. I hope that, as well as resulting in the award of a doctorate, this work will be used by others in the field to improve involvement practice.

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## Appendices

### Appendix 1: Personal history

I am a divorced white woman, I was born in 1957 in a north London suburb. The area was middle class, with many streets of three-bed semi-detached houses. Mum was 42 years old when I was born, Dad was 52. Mum's family came from Tottenham. Dad and his first wife were from North Wales from a town dominated by a steel manufacturer. I have an older step brother and sister from my father's first marriage, who were eighteen and twenty five when I was born. My step sister and brother were young when their mother died, and they moved to London after my parent's marriage. I had an older sister who was drowned in 1956 when she was six; I was born ten months after her death.

My childhood memories are of an orderly household, Mum was at home, my sister lived at home and worked as a domestic science teacher, my brother was at university doing chemical engineering. Dad spent a lot of time working away from home; he had one of the few cars in our road. Reading was my first passion, my second was riding; much of my spare time was spent 'up the farm' where groups of keen children looked after the ponies and rode in the surrounding fields and lanes.

My Dad died when I was 14 from lung cancer, just after his retirement. My Mum was deeply sad; we had a very bleak time together in my teenage years.

I went to a large co-educational selected entry school where it took me some time to find my feet because my primary school was a small private convent for girls. I had a high quality exam oriented education and followed the school 'norms' applying to Southampton University to study politics and economics at 18. I got a full grant to go to University which included payment of fees - if I did some work in the holidays I could live on my grant in the term time. The education system has been good to me; my PhD is also funded with a bursary.

Although I did well at University I was not confident and had no idea what I wanted to 'do'. I chose to do a secretarial course and got a job at the London Business School as a secretary, ending up as an administrator of a research centre. I enjoyed work, it was privileged and sociable, and I was good at my job. I stayed there until I split up with my husband, who I had been with for seven years. The separation was traumatic and I was

responsible because I had started a relationship with a colleague; in this period I first went to a counsellor. I left work and went travelling alone in response to this difficult period.

On return I got a job as a trainer in communication skills, but I found training in a commercial environment difficult because many people were 'sent' on courses and they were not motivated. I wanted to work in a situation where work had more meaning and with people who were committed and I moved into the voluntary sector. At Breast Cancer Care I worked with women who had been affected by breast cancer, training them to support other women with the diagnosis. I stayed in the organisation for nearly 10 years.

Starting a therapeutic process when I left my husband proved very significant for me. I began to reflect on myself and my family, and began to unearth significant personal issues. I have spent over 20 years in psychotherapy, which has been a positive and supportive process, but also contributed to my diagnosis with bi-polar disorder. Therapy did not make me ill, but it uncovered issues that had been buried for good reason, and working on key issues in therapy led to my first psychotic episode.

In the mid 1990's I moved to South Wales from West London with my partner, I continued to work in London part-time, started a Master's degree at Bristol University and also started gestalt psychotherapy training. This was deeply satisfying and I spent 5 years training and started a private practice as a trainee psychotherapist.

In 1998 I had my first psychotic episode as a result of some intense therapeutic work. At the time it was seen as a one-off response to stress. However, two years later, when I had separated from my partner and was living with a friend in Bristol, I had another episode and I was detained in hospital under the Mental Health Act. This episode was followed by a severe clinical depression, and at this point I was diagnosed with bi-polar disorder – I was 43 years old. Initially I did not accept the diagnosis and refused to take medication. Over a year I had four episodes of illness, two manic episodes and two clinical depressions. Eventually I accepted the diagnosis and took mood-stabilising medication.

Being diagnosed with a serious mental illness and being detained under the mental health act was traumatically different from knowing that I had some personal issues that I was addressing in therapy. Suddenly I experienced the gulf between being what a psychologist friend calls 'one of the worried well' and being 'mad'; between needing psychotherapy and needing the attention of specialist mental health services. It felt like I had crossed an invisible boundary to inhabit another world. Although the experience of

being psychotic was damaging and distressing, clinical depression was a far worse experience. It felt like being in torment every moment, howling in pain in a deep dark prison that was invisible to others. The desperation and despair of this experience were overwhelming. Going manic was like getting high without drugs, at first a delight, infused with energy and ideas, experiencing the world intensely, both physically and emotionally. Poetry and music were transformed, and I had very 'spiritual' experiences. I was confident and happy. The first time I went psychotic the process of moving from being 'ordinary' to being 'mad' took about a week, but in later episodes the process was quicker, only taking only one or two days before becoming really ill. The experience of psychosis is of fleeting moments – from inside I am wholly in my thoughts and ideas, with no reflexivity – no sense of who I am to others, from the outside. In this state whatever is thought is real, as real as 'ordinary' experience. Behaviour makes sense from inside. My psychotic experience had terrible moments, but memory is fragmented, vivid pictures with gaps, disconnected. Much of what I do is lost, unknown. No self without memory. Psychosis is uninhibited, jumbled, fast, strong moments immediately forgotten or supplanted. Shame comes later. Coming back – realising. Knowing and not knowing what was done. Feet back on the ground, others exist again, their gaze, their experience of me lives again. Pieces taking a while to realign, settle back into place, identity has to reform, cohere.

My friends and family helped me to stay safe before I was admitted to hospital – so they have been exposed to my madness. Although they were very supportive and helpful, going through such experiences with me had a significant impact, casting a shadow. Being detained has many other practical implications, for driving, insurance and travel. This was an extremely difficult period for me - I was on state benefits and claiming disability living allowance. I was unable to work and it became impossible for me to continue my psychotherapy training or to work as a therapist. Absorbing these losses was an extremely painful process, in which I felt that my identity had been radically altered. The future seemed very bleak and I thought I would never work again.

However, in time I began to recover. Mood stabilising drugs worked for me, allowing thought of life less dominated by illness. Because I had worked in the voluntary sector I understood that there would be opportunities to volunteer. I found out about local mental health charities, which led me to Bristol Mind. At this point I just wanted something to do, something to give shape and meaning to my days. Despite training as a psychotherapist I found that I knew little about mental health problems or mental health

services and I wanted to understand more about my own experience and the services that I was using. Bristol Mind was in walking distance and offered a number of opportunities. By chance I came across the User Focussed Monitoring (UFM) project which I was encouraged to join; it was evaluating acute care services in Bristol. The project had already been designed and data were being collected. I went to meetings and sat in on some interviews. This began a process of rediscovering that I still had some of my prior skills and knowledge and rebuilding confidence to take a place in the world again.

As well as working on the UFM project I got involved in a variety of service user meetings run by the local council and the local mental health trust, so I met other people with mental health problems outside a hospital setting. It was shocking to discover that some people's lives were dominated by experiences of illness over many years and how limited some people's lives were. I was part of a marginal social group, characterised by poverty, absence of paid work, recurring illness and severely limited opportunities. I was shocked by other users' anger about services and their treatment. For some health professionals were oppressors who were out to get them, they had been made to take unwanted drugs which did not work and had difficult side effects. They had been locked up, held down and forcibly treated. While I had had similar experiences, generally I felt that health professionals and services were trying to help me. Once I had decided taking psychiatric drugs was a better option than continuing episodes of illness, I found that treatment worked for me, this experience was sometimes awkward with my peers.

With hindsight I can see I went through a process of encountering my own preconceptions and prejudices about madness. Despite seeing myself as having personal 'issues', training as a psychotherapist and identifying with people with psychological problems it was something else to be 'mad'. I became a strange other in a different world. My response was to embrace my new identity by taking on roles where I was clearly identified as a 'mental health service user'. I did this because it felt impossible to be the person I was before – that person had gone and I could not pretend. Embracing the role also offered opportunities – working on the UFM project led me into new places. I joined a group of service users doing a project exploring the loss of occupation following mental health problems; I took on work to implement some changes to acute services. I discovered that I did have skills, and I was able to manage responsibilities.

I did a self-management course at MDF (the Manic Depression Fellowship). This was a three day programme where I met people who were both bi-polar and had real lives, one was even a psychiatrist! The course was helpful in itself, encouraging a more active

approach to staying well and coping with being ill, and it led to another opportunity. The facilitators had bi-polar and they were recruiting, so I applied and worked as a facilitator for several years, co-running about ten courses. I learned a lot about bi-polar disorder, and how both similar and different experiences could be. Doing the work felt risky, my psychotherapist self was alarmed. I feared not knowing what to do if participants were ill or distressed. There were difficult times – occasionally people were too ill to participate on the course, and reflecting on the impact of the illness was very distressing for some participants – and running the courses was very rewarding. Groups bonded easily, people supported each other, and it was possible to laugh about the outrageous realities of our experiences. For some the course had a big impact, a spark that helped them to see what they could do to make their lives better. Looking back it is strange to think that mental health services at the time did not help people to do this – they often seemed to encourage passive acceptance of a limited life on drugs supported by others. I hope that the stronger focus on recovery means that more people are encouraged to appreciate their skills and qualities, to explore what they can do rather than being focused on their limits, to live rather than exist.

These experiences were the start of a new life which has continued to unfold in unexpected ways. Over the next few years I took on a variety of roles and tested my capacity to take responsibility and survive. I chaired a group including professionals and service users following the UFM project, which worked to improve acute services. We produced a booklet for everyone admitted to hospital in the local NHS Trust. As a result I became a member of the Acute Care Forum in the Trust. I was employed as a clinical governance reviewer by the Commission for Health Improvement (later the Healthcare Commission). This was a challenging role which included talking to patients before review weeks, and participating as a full member of a review team. My work as a service user researcher developed, I became co-lead of the project on loss of occupation. Ten service users were involved; six were core members who became friends. We were supported by the Strategies for Living project at the Mental Health Foundation which provided training and ongoing help through the research process. This was a challenging and rewarding experience. Later we presented our work in a variety of places and contributed to an initiative led by the local council, which included health professionals and staff from the voluntary sector.

My life at this point was varied and active. While I was doing some quite challenging things I had no ongoing responsibilities. It was strange that taking up a position of ‘mental

health service user' offered so many opportunities. During this time I was on incapacity benefit and disability living allowance but it seemed likely that at the next medical assessment I would be seen as capable of work, particularly if the Benefits Agency knew the full extent of my activities. Financially I could not afford to work part-time; my rent and council tax cost nearly £600 per month. While I did feel ready to take on part-time work I did not have that option.

It was lucky to be told about a job for a service user researcher on a multi-site project which was looking at the practice of involuntary hospital admissions, its outcome and predictors of outcome. Each of five study sites recruited a full-time service user researcher and I got the Bristol based job. This was a difficult experience. Most people in the department were psychiatrists or psychologists as well as academics. I was the only 'out' service user. I worked in a team lead by a consultant psychiatrist and epidemiologist, with a forensic consultant psychiatrist and a research fellow. While they were friendly and supportive the academic environment was strange and I did not feel I belonged. On a day to day basis I mainly worked with the research fellow. I was trying to pace myself in my first job and stay well in an environment which expected fast performance. My role as research assistant was different from my expectations; I had to recruit study participants and then administer a number of quantitative questionnaires, which included doing a clinical assessment (the GAF - global assessment of functioning). My recruitment figures were the worst across all the sites, but despite feeling pressurised I knew that I would not do more to 'push' people to take part. It was difficult to spend all my time in acute wards talking to people who had just been detained. I was given support in my role from one of the psychiatrists but despite this I was unhappy. I decided I could not continue in the role and left after about 9 months in post. Towards the end it became clear that my retention rates were best in the research team – we saw people four times – and this was clearly important for the research design. However, this recognition came too late for me. One positive aspect of this experience is that I did not have an episode of illness despite feeling stressed and unhappy.

Over this period I was still in contact with friends at Bristol Mind which had an active user-led research project. Bristol Mind was awarded a Big Lottery funded research grant which was recruiting for a lead researcher and I applied and got the job. It was shocking to discover that I had moved from being a research assistant to chief investigator! I had to learn a lot to do the job at Mind and was fortunate to have a really strong Steering Group. However, the four key members had not worked together before and I was surprised to



discover they did not always agree about research processes. Just after I started the job I had a psychotic episode and was detained in hospital; we were in the process of recruiting two user-researchers and I liaised with Mind from the acute ward. Despite the challenges, I felt very differently in this job, I 'belonged' at Mind and a lot of personal and supervisory support was built into the role. Nonetheless I had to deliver a £300,000 project to time over three years. This work gave me confidence that I could operate to a good standard consistently, and there were many challenges. This included managing the other user researchers, drowning in a sea of data – we did 72 semi-structured interviews and ran five focus groups - and writing a large project report.

Alongside my paid work I continued to have some involvement in other projects. After working at Bristol Mind I took some time out and in this period started to get involved in the Service User and Carer Group in Research at UWE. Making this link has led to another group of related opportunities which have brought me to my PhD project. In the last few years I feel as if I have stepped back a bit and become more interested in thinking about public involvement in research. I am most interested in how research partners can work with academics and clinicians in conventional research settings i.e. not in user-led research, and in research areas other than mental health. It is only relatively recently that I have made the shift into a more 'academic' perspective. Although I had a lot of experience of being involved in service development, evaluation and inspection as well as research until recently I had not read much academic about 'public involvement' as such.

### **What have I learned?**

As I look back over this period I can see I have learned some important lessons – firstly, not to be so afraid of madness and other mental health problems. Madness is terrible, traumatic, outrageous, desperate, hilarious, weird – anything and everything. Despair is dark, deep and dreadful. Such strange and frightening experiences are more known, more seen, and bearable in short doses. I know that the worst will not necessarily endure.

Mental health service users are not a homogeneous group. I met people with very varied lives and experiences as well as similarities. Some became friends, and others have different values and attitudes, are annoying, dreadful, boring ... just like anyone. At first I was drawn to spending time in groups of service users, over time this has diminished. I am now less accepting and tolerant of people who remain defined by their use of services. I am fortunate; I have stayed well and found a different life, so in part my shift is a

reflection of my own journey with changing interests. But it is hard to be with people who are trapped by experiences of illness, by lack of confidence and opportunity, by lack of money. I think this is a fear of what might have been for me.

I learned that it can be difficult to work with other users, focusing on a task may need to accommodate personal needs and illness. Many meetings combined a focus on task and seeking/providing support. As someone who is quite task oriented this can be difficult for me. It was particularly difficult as a paid worker leading a team of user researchers when I was responsible for delivering the research project on time to the funders. One colleague had frequent periods of depression but wanted to continue at work. This was difficult to manage for me and the third team member. Part of me just wants people to be able to get on with their work. Coping with personal needs alongside delivering project tasks is a challenge.

I have found that I am not always that good at being with people who are ill. At times I can be supportive, be there for my friends, but sometimes I don't want to revisit those places. In particular I have a limited capacity to be around deep depression. This is a difficult experience for anyone, because at some level we know how the other is suffering and it is hard to be helpless in the face of such pain. In addition for me it is a reminder of my own darkness.

I have learned a lot about mental health services and treatments – and a core lesson is that in this field everything is contested. I find this personally difficult and frustrating, there are too many perspectives, so understanding is always undermined. For some there is no such thing as madness, it is constructed by others and by society. But I think I do go mad and recover from madness – so I struggle to see how this process is 'constructed' by others. It is triggered by particular situations which I can describe and avoid. Clearly madness is interpreted in the world in a variety of ways, some people are inspired, holy, visionary, being bi-polar can be linked to being a creative genius or comedian. But many of us are not so fortunate, populating the edges of society, poor, marginalised. Many are homeless, addicted to alcohol or street drugs, in prison, alone, unwanted, outside. For me my vulnerability seems to be a response to circumstances. In some ways it is much easier to have a disease which results in biochemical imbalances in the brain than to be a damaged person with difficult history. If you have a disease it makes sense to 'treat' it. A stereotype of psychiatry is that mental health problems need pharmacological treatment. Psychiatric drugs certainly play a central role and are at the centre of contest. Scientific 'evidence' says they work, but many people find they don't work for them. Some people

don't want such drugs on principle as they affect their brain and mind. Others don't want them because they don't seem to work or work to some extent but also have significant problematic side effects. Other treatments are also contested – it is not clear whether talking therapy works, some things work for some people, but it is not clear what works for who. The services you receive can still be a lottery, I know a young person in another part of the South West who is sinking into depression and inaction after a diagnosis of bi-polar in an area renowned for its focus on recovery.

To me it seems that what people expect from mental health services is very different. Service users want respite from certain experiences, may want to be cured, or to be able to get on with their lives, to understand themselves and what happens to them, to cope with trauma and difficult relationships. Health professionals, in particular psychiatrists, seem to have more limited ambitions; they seem only to want people to stop having particular symptoms. In the face of such persistent growth in mental health problems across the world perhaps such limited ambitions are understandable. If symptoms stop, or the worst aspects of symptoms stop, treatment can be seen as successful. However, in my experience this is not all that service users want, so treatment, even when it works, can leave people feeling that one step has been taken but that they are left to struggle with other difficulties. Many people seem to be asking why services get them over a crisis and then abandon them to a hinterland which can turn into a lasting landscape of life limited and curtailed? People look to services for help with their lives not just their mental health problems.

I've learned that embracing the identity has led to opportunities that I did not expect, to a career as a user even though I don't use mental health services any longer. I don't think that I am well for good and I still fear getting ill – but I have found that I can withstand quite a lot of ordinary life stress and stay well. The diagnosis can also be a shield I can use to protect myself and to get support. I am the kind of user that some people want; a user who is like a 'real' person, a well person, who does not need special looking after or support, who can work out what is needed and fit in. Fitting in is a core skill in the different places I have inhabited in involvement roles.

It is strange to realise that as a mental health service user I took on roles that were more demanding than many of my prior work roles, for example, running courses for fifteen people with bi-polar disorder and being part of a clinical governance inspection team for NHS Trusts. These roles could be accomplished despite the 'service user' tag.

My relationships in and around my PhD project were quite complex, I am both PhD student, colleague and research partner. I have a number of relationships that pre-date my project, with my director of studies, with another supervisor, with staff at UWE and with researchers and health professionals in mental health. I also have established relationships with a number of active and experienced research partners; who I am in these relationships shifts subtly over time and in different contexts.

As a result of my experiences I have a lot of ideas, feelings, 'theories' about myself and about involvement, but many of them are not easy to identify until a situation arises in which they become clear. I am very used to being 'out' as a mental health service user and person with a 'SMI' (Serious Mental Illness) but I do not know the impact of such disclosure on others. However, I have generally had positive experiences of self-disclosure, and others have disclosed significant personal information to me subsequently. I have disclosed my service user status routinely in this PhD, and doing so is in part a political statement, an effort to be seen as both having a serious mental health problem and as capable. At times I feel guilty about making a 'career' of my illness – getting on and being OK is not necessarily a 'good thing' in all contexts and sometimes with other mental health service users I tone myself down. There is guilt about getting on better than other colleagues with mental health problems.

I first wrote this account of myself in October 2011 and discussed it in supervision. This is a revised and shortened version. Long-term psychotherapy and therapy training means I am very practiced at self-reflection and thinking about how I contribute to events, to my part of any process that unfolds. This account is familiar to me but unfamiliar as part of a thesis; it is also an 'authorised' account - it is the one I wish to tell.

## **Appendix 2: What is public involvement in research?**

INVOLVE defines public involvement in research as research being carried out **'with'** or **'by'** members of the public rather than **'to'**, **'about'** or **'for'** them. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials, undertaking interviews with research participants.

When using the term 'public' we include patients, potential patients, carers and people who use health and social care services. Whilst all of us are actual, former or indeed potential users of health and social care services, there is an important distinction to be made between the perspectives of the public and the perspectives of people who have a professional role in health and social care services.

### **What public involvement in research is not**

Researchers and others use different words to describe public involvement, for example words such as engagement and participation. When INVOLVE uses the term 'public involvement' we are not referring to researchers raising awareness of research, sharing knowledge or engaging and creating a dialogue with the public. We are also not referring to the recruitment of patients or members of the public as participants in research. However, these different activities – involvement, engagement and participation – are often linked and although they are distinct can complement each other. For example, the public can and do play a valuable role in advising on recruitment of patients as participants and on ways of engaging with the public.

**INVOLVE** uses the following terms to distinguish between the different activities:

**Involvement** – where members of the public are actively involved in research projects and in research organisations. Examples of public involvement are: as joint grant holders or co-applicants on a research project; involvement in identifying research priorities; as members of a project advisory or steering group; commenting on and developing patient information leaflets or other research materials; undertaking interviews with research participants; user and/or carer researchers carrying out the research.

**Participation** – where people take part in a research study. Examples of participation are: people being recruited to a clinical trial or other research study to take part in the research; completing a questionnaire or participating in a focus group as part of a research study.

**Engagement** – where information and knowledge about research is provided and disseminated. Examples of engagement are: science festivals open to the public with debates and discussions on research; open day at a research centre where members of the public are invited to find out about research; raising awareness of research through media such as television programmes, newspapers and social media; dissemination to research participants, colleagues or members of the public on the findings of a study.

Adapted from the INVOLVE website (INVOLVE 2013).

## Appendix 3: Advisory Group Terms of Reference



### Advisory Group

**PhD project title:** *What is going on in public involvement in health research? An ethnographic exploration of the aims processes and outcomes of public involvement in three health research studies.*

#### Terms of Reference

##### **Purpose:**

The aim of the Advisory Group is to:

- Make sure the views of research partners, researchers and research managers are considered throughout the PhD project.
- To advise and give feedback on overall plans and specific proposals related to the project.
- To provide specific input on identified tasks – for example doing pilot interviews.
- To raise questions, issues or concerns that may be of relevance for the project.

##### **Responsibilities:**

Rosie Davies is responsible for:

- Arranging Advisory Group meetings and providing administrative support including action notes of meetings.
- Providing appropriate information about the PhD project including background information as necessary.
- Describing potential areas for advice or feedback and identifying potential tasks for members.
- Providing support or training to members as required.

Members are responsible for:

- Attending and participating in Advisory Group meetings and other agreed activities.
- Reading information provided for meetings in advance.
- Giving feedback and advice on identified issues/areas.
- Raising any areas of concern or that might need consideration.
- Responding to questions or participating in identified tasks as agreed.

**Membership:**

[REMOVED]

**Additional Information**

- The Advisory Group will meet twice a year at UWE Glenside. Dates to be agreed with group members.
- Members may be contacted as a group or individually in addition to meetings for informal advice and feedback.
- The PhD project and Advisory Group will continue until the Autumn of 2013 (official end date 1.9.13).
- PhD supervisors are: Professor David Evans (Faculty of Health and Applied Sciences, UWE), Professor Jane Coad (Coventry University) and Dr Nick de Viggiani (Faculty of Health and Applied Sciences, UWE).
- Rosie Davies is the main contact and will provide support and information as necessary.
- Research partners will be offered payment for Advisory Group work at the current UWE rate (£19.47 per hour). Any out of pocket expenses will be covered for all members.

Rosie Davies

April 2012



**Appendix 4: Panel ratings on the feasibility of evaluating the impact of public involvement on research processes, outcomes and stakeholders**

<b>Impact issue: How feasible do you think it would be to evaluate the impact of public involvement on...</b>	<b>Feasible to evaluate (defined as 80% or more of panel providing a high rating)</b>
<b>Research processes</b>	
Identifying topics to be researched	<b>Yes</b>
Prioritizing topics to be researched	<b>Yes</b>
Commissioning research	No
Research design	No
Managing research	No
Collecting data	No
Analysing research findings	No
Interpreting research findings	No
<b>Research outcomes</b>	
Disseminating research	<b>Yes</b>
Determining the usefulness of research findings	No
Implementing research findings	No
The overall quality of public involvement in a research study or research-related activity	No
The overall quality of the research	No
The overall impact of the research	No
<b>Stakeholders</b>	
The member(s) of the public involved in the research	<b>Yes</b>
The member(s) of the research team	<b>Yes</b>

Adapted from Barber *et al.* (2011 p. 232)

## Appendix 5: Semi-structured questions for initial interviews with research partners

1	<p>Can you tell me how you came to be working on this study?</p> <p>What stage was the study at when you got involved?</p> <p>What influenced your decision to get involved?</p> <p>Do you know the history of involvement?</p>
2	<p>Have you worked as research partner on other studies?</p> <p>If yes, could you tell me more about your previous experience/s of being involved?</p> <p>Have you done any other kinds of public involvement/voluntary or community work?</p>
3	<p>What did you expect when you first got involved?</p> <p>What do you expect from the researchers?</p> <p>What do researchers expect from you?</p> <p>Do you have any kind of contract/formal agreement?</p> <p>What is the structure of involvement here? Advisory group; panel; co-researchers; individuals ...</p>
4	<p>How did you get recruited to help with this study?</p>
5	<p>What happened when you were first involved?</p> <p>Was there any induction or training for the study or the role?</p> <p>Did/do you need any training?</p> <p>Do you have the information you need to contribute?</p> <p>How are you supported?</p> <p>Networking events, annual gatherings, informal meetings.</p>
6	<p>Are there any structures or procedures for involvement here?</p> <p>Any discussions about how you work with researchers regarding confidentiality or other ethical issues?</p> <p>Advisory group on PPIR/ committee with partners on it</p> <p>Policies – informal or formal?</p>
7	<p>What has working on this study been like for you so far?</p> <p>How does the reality compare with what you expected?</p>
8	<p>Do you know what the researchers want you to do (your role)?</p> <p>For example, the jobs/tasks they want you to contribute to?</p> <p>Have you understood your role from the start?</p>

9	Do you feel you have the skills and experience you need to contribute to the study?
10	What specific jobs/tasks have you contributed to on this study? What was it like to help with that task/job? (for each job/task) What was the scope of the job? How often have you done this job?
11	Do you get paid for your time or for out of pocket expenses? [vouchers; pay; expenses] Are there any issues about payment for you? Any non-monetary rewards?
12	What are your relationships with the researchers like?
13	Do you think you have made a difference to the research study so far? If yes, how? What difference? Example.
14	Has being a research partner had an impact on you? If yes, how?
15	Has your taking part had any other effects that you have noticed? For example on anyone else?
16	Do you think that the type of study this is, and/or being here in this institution has had any effect? If yes, please describe the effects
17	Is there anything else that you would like to say or that you think I should have asked about?

**Appendix 6: Semi-structured questions for initial interviews with researchers.**

1	<p>Can you tell me how you came to be working on this study?</p> <p>What stage was the study at when research partners got involved?</p>
2	<p>How did research partners come to be involved in this study?</p>
3	<p>Have you worked with research partners on other research studies?</p> <p>If yes, could you tell me more about how you have worked with research partners in other studies?</p>
4	<p>What did you expect of research partners when they started working on this study?</p>
5	<p>What has working with research partners on this study been like so far? How does the reality compare with what you expected?</p>
6	<p>Did you have specific jobs/tasks in mind that research partners might help with?</p> <p>If yes, what tasks?</p> <p>If yes, was there a role description?</p>
7	<p>How were the research partners identified and recruited?</p> <p>Was there any selection process?</p>
8	<p>How were research partners introduced to the study and their role?</p> <p>Any induction?</p> <p>Any training?</p> <p>Any provision of information?</p>
9	<p>Have you had any discussions with research partners about confidentiality or other ethical issues?</p>
10	<p>Do you feel the research partners have the skills and experience they need to contribute to the study?</p>
11	<p>What specific jobs/tasks within the research study have research partners contributed to?</p> <p>How have research partners contributed to that job/task? (for each one)</p>

12	<p>Do research partners get paid for their out of pocket expenses and/or time?</p> <p>Have there been any issues around payment of research partners?</p>
13	<p>What are your relationships with research partners like?</p>
14	<p>Do you think the research partners have made a difference to the study so far?</p> <p>If yes, how?</p> <p>What difference?</p>
15	<p>Has working with research partners had an impact on you?</p> <p>If yes, how?</p> <p>What impact?</p>
16	<p>Has having research partners involved had any other effects that you have noticed? For example, on anyone else?</p>
17	<p>Do you think that the type of study this is and/or being here in this institution has had any effect?</p> <p>If yes, please describe the effects.</p>
18	<p>Is there anything else that you would like to say or that you think I should have asked about?</p>

## **Appendix 7: Reflection on the development of the methodology**

My thinking about epistemology, methodology and methods evolved over time; I started with an assumption that I would undertake a qualitative project because I had relevant skills and experience. Despite a strong current in the literature pushing for quantitative research (Staniszewska *et al.* 2011b) I was not sure what should be measured or how, nor was I sure how such an approach could reflect the complex situations I had encountered in my involvement experience.

This project was rooted in practical involvement experience as a service user and engaging with philosophical ideas and methodological literature was daunting. In my PhD application I proposed a grounded theory study, because I was attracted by its empirical approach and aim to build theory from close attention to data. However, as my thinking developed, I became clearer that I did not want to generate new theory but to assess the utility of existing ideas in relation to my data. The literature already offered conceptual frameworks, none of which seemed to have been used extensively, so the theoretical work needed was synthesis and assessment, not necessarily new theory.

My awareness of the need for observation prompted consideration of a more ethnographic approach and while reading about field notes (Emerson, Fretz and Shaw 1995) I realised that writing descriptions of events necessitated interpretation; this led me to identify problems with induction. Therefore, grounded theory and an inductive approach did not fit, but taking a deductive approach was also problematic. Conceptual thinking on involvement in research was still developing (Brett *et al.* 2010, Staniszewska *et al.* 2011a), so there was no body of theory supported by a consensus available to test. These problems led me to abduction and phronesis, which are oriented towards praxis.

I was seeking well informed and accessible theoretical tools that would support better navigation between thinking and practice, and my project evolved into an attempt to identify or create such tools. My interest in theoretical development was therefore pursued in relation to a rich description of empirical data, as a foundation for understanding and assessing the potential utility of ideas. This developmental process led to the position described in chapter 3.5.

## Appendix 8: Short description of project

### What is going on in public involvement in health research?

*An ethnographic exploration of the aims, processes and outcomes of public involvement in three health research studies.*

This doctoral research project is funded by the University of the West of England (UWE) in Bristol, based in the Faculty of Health and Life Sciences. It is part of a programme of research on public involvement. The project aims to describe and make sense of what is going on when the public are involved in three health research studies. It will be qualitative, taking an ethnographic approach, and data will be gathered by observation, interview, collection of documents and photo elicitation. Data will be gathered from each research study for a period of up to eighteen months.

I am interested in this subject because I have worked as a service user researcher and research partner (my term for a member of the public helping professional researchers) for ten years and my experience suggests that what happens in public involvement in health research in practice differs from descriptions of it in policy and academic literature.

There is government policy which encourages public involvement throughout the research process. Members of the public involved in a research study might be helping in a variety of ways. This could include study design, choice of outcome measures or making written information accessible for research participants.

#### Implications of taking part

Data collection will begin in the autumn of 2011. The three case studies will be recruited at intervals and data will be collected over a period agreed with each study ending in May 2013. Participants will include professional researchers, research partners and may also include other staff or research managers.

Data collection will include participant and non-participant observation of research study activities, interviews with researchers and research partners, collection of study documents and photo-elicitation. The number of researchers interviewed will depend on the size of the research study. It will be optional whether or not participants take photographs. Data collection will include the collection of contextual information.

Agreeing to take part in my project does not imply unrestricted access to all research activities. Access will be negotiated and renegotiated as the project progresses. What is observed and who is interviewed would be agreed in initial discussions about the project and as it proceeds.

#### Benefits of taking part

Taking part in this project will contribute to building the national evidence base around public involvement in research. In addition, the project will offer an opportunity to reflect on the practice of public involvement. Findings will be written up in a short report for participants and an event to discuss project findings will be offered.

Rosie Davies

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The information in this box is adapted from **INVOLVE** which is a national advisory group supporting greater public involvement in NHS, public health and social care research.

The **public** includes, for example

- patients and potential patients
- people who use health services
- parents, relatives, guardians
- disabled people
- organisations that represent people who use services.

**Public involvement** means an active partnership between the public and researchers in the research process, rather than the use of people as the 'subjects' of research. Many people define public involvement in research as doing research 'with' the public, rather than 'to', 'about' or 'for' the public.

More information is available from:

[http://www.invo.org.uk/About\\_Us.asp](http://www.invo.org.uk/About_Us.asp)

## Appendix 9: Rosie Davies short CV

### Rosemary Laura Davies

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### EXPERIENCE

#### **INVOLVE, NIHR national advisory group on public involvement in research**

*Appointed as a member*

*February 2012 for 3 years*

#### **Faculty of Health and Life Sciences, UWE**

*Full time PhD student*

*September 2010-date*

‘What is going on in public involvement in health research?’

#### **People and Research South West based at Faculty of Health and Life Sciences, UWE**

*Research partner*

*May 2011-date*

Member of Reference Group and Steering Group for this consortium of local research organisations collaborating on public involvement in research.

#### **School of Social and Community Medicine, University of Bristol**

*Service user research partner*

*2008-date*

Co-applicant on NIHR programme of research on suicide prevention and service user research partner. Previously on Steering Group for CONTACT study conducted by Professor David Gunnell.

#### **Avon and Wiltshire Mental Health Partnership NHS Trust**

*Service user research partner, Research and Development Committee*

*2007-date*

#### **Faculty of Health and Life Sciences UWE**

*Research Partner and co-applicant*

*2010-date*

NIHR Health Services Research/INVOLVE funded research project which aims to assess the impact of public involvement in research through a realist evaluation. Eight case studies undertaken jointly by academic researchers and service user research partners.

#### **Service User and Carer Involvement in Research Scheme,**

#### **Faculty of Health and Life Sciences, UWE**

*Co-chair Steering Group*

*March 2009 –December 2010*

The Faculty of Health and Life Science has a scheme to support meaningful and effective user and carer involvement in research.

*Member*

*December 2010-date*

This scheme has been renamed Public Involvement in Research

#### **Faculty of Health and Life Sciences, UWE**

*Project Worker*

*July 2009 –May 2010*

Carried out a scoping study on public involvement in research to find out how research active organisations might collaborate to improve involvement. This work was funded by fourteen stakeholder organisations in Bristol and the South West of England. As a result of the scoping study a local collaboration ‘People and Research South West’ has been funded and set up to support public involvement.

#### **Service User and Carer Involvement in Research Scheme,**

#### **Faculty of Health and Life Sciences, UWE**

*Temporary support and outreach worker*

*May 2009 –July 2009*

Appointed to do short term support and outreach work prior to the launch of the scheme.

#### **Bristol Mind**

*Research Co-ordinator/Chief Investigator*

*April 2005-September 2009*

‘Effective involvement in mental health services: Assertive Outreach and the Voluntary Sector’. A Big Lottery Funded qualitative project that explored how voluntary and statutory services could best work to promote effective access to services for people with severe mental illness who are labelled as ‘hard to engage’. A service user led study sponsored by the Avon and Wiltshire Mental Health Partnership NHS Trust and supported by academic partners from Bristol University and the South West Development Centre.



## EXPERIENCE continued

### **Academic Unit of Psychiatry, University of Bristol**

*Research Assistant 'Outcomes of Involuntary Hospital Admission Study' June 2004-March 2005*

This study aimed to provide evidence about the practice of involuntary hospital admission, its outcome and the predictors of outcome. The main outcome was patients' assessments of the justification of coercion, and whether perceptions changed over time. Employed specifically as a service user researcher recruiting study participants and collecting data. This included the administration of a psychiatric assessment the Global Assessment of Functioning (GAF).

### **Strategies for Living, Mental Health Foundation**

*Co-running research project 'Life's Labours Lost'*

*March 2002-2004*

This project involved a team of ten service user researchers, all volunteers. The research focused on the experiences of people who lost work following mental health problems.

### **Bristol Mind**

*User Focused Monitoring (UFM) Volunteer Project Worker*

*October 2001-2004*

Key features of UFM are that service users develop the research instruments, administer the research and interpret the results. Contributed to one study on Acute Adult Inpatient Services in Bristol, and to subsequent implementation work led to the production and use of an information booklet for all patients in acute psychiatric wards within the Avon and Wiltshire Mental Health Partnership NHS Trust.

## PUBLICATIONS

Davies, R. and Evans, D. (2010) *Public Involvement in Research. How can organisations collaborate to improve involvement?* Produced at UWE on behalf of fourteen stakeholder organisations in Bristol and the South West. Available from the UWE website: <http://hls.uwe.ac.uk/suci/Default.aspx?pageid=9> April 2010.

Davies, R., Shocolinsky-Dwyer, R., Mowat, J., Evans, J., Heslop, P., Onyett, S., Soteriou, T., (2009) *Effective involvement in mental health services: the role of assertive outreach and the voluntary sector.* Report by Bristol Mind: Bristol. Available from Bristol Mind, 35 Old Market Street, Bristol BS2 0EZ. Telephone 0117 980 0370. Website: [www.bristolmind.org.uk](http://www.bristolmind.org.uk)

Davies, R. (2009) *Influencing change: Outcomes from User-Focused Monitoring (UFM) inpatient research in Bristol in 2002* Chapter 10 in Sweeney, A., Beresford, P., Faulkner, A., Nettle, M., Rose, D. (2009) *This is Survivor Research* Herefordshire:UK PCCS Books Ltd pp 98-106

Boldison, S., Davies, R. Hawkes, H., Pacé, C., Sayers, R. (2007) *Employment, Mental Health and PSI: Occupation is Everyone's Job* Chapter 11 in Velleman, R., Davis, E., Smith, G., Drage, M. eds., (2007) *Changing Outcomes in Psychosis. Collaborative Cases from Practitioners, Users and Carers* Oxford:UK BPS Blackwell pp 194-210

Bodman, R., Davies, R., Frankel, N., Minton, L., Mitchell, L., Pacé, C., Sayers, R., Tibbs, N., Tovey, Z., & Unger, E. (2003) *Life's Labours Lost. A study of the experiences of people who have lost their occupation following mental health problems.* Supported and funded by the 'Strategies for Living' project at the Mental Health Foundation. Available from [www.bristolmind.org.uk](http://www.bristolmind.org.uk)

Bristol Mind User Focused Monitoring Project (2001) *A User-Focussed Study of Three Inpatient Units in Bristol*, Bristol Mind: Bristol Available from [www.bristolmind.org.uk](http://www.bristolmind.org.uk)

## EDUCATION AND QUALIFICATIONS

### **University of the West of England, Bristol**

*Postgraduate Certificate in Applied Social Research (Merit)*

*September 2011*

### **University of Bristol, School for Policy Studies**

*Master of Science with Commendation*

*1998*

Course title: **Management Development and Social Responsibility.**

### **University of Southampton**

*Bachelor of Science in the Social Sciences. Upper Second ~ Politics*

*1978*

## **Appendix 10: Research protocol vs 4**



University of the  
West of England

# What is going on in public involvement in health research?

An ethnographic exploration of the aims, processes and  
outcomes of public involvement in three health research  
studies.

## **Research Protocol – Version 4.0**

**Rosemary Davies**

20 December 2011

## Contact details:

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### ***Director of Studies:***

Dr David Evans  
Professor in Health Services Research (Public Involvement)  
Centre for Health and Clinical Research  
Associate Head of Department (Research and Knowledge Exchange)  
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# **What is going on in public involvement in health research? An ethnographic exploration of the aims, processes and outcomes of public involvement in three health research studies.**

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## **Short title: What is going on in public involvement in health research?**

### **INTRODUCTION**

This doctoral research project aims to describe and make sense of what is going on when the public are involved in three health research studies. The project will be qualitative, taking an ethnographic approach, and data will be gathered by observation, interview, collection of documents and photo elicitation. Data will be gathered from each research study for a period of up to eighteen months. I am interested in this subject because my experience suggests that what happens in public involvement in health research in practice differs significantly from descriptions of it in policy and academic literature. Barber, Boote and Cooper (2007) also identify this problem.

Public involvement in research has been described by INVOLVE (the national advisory group supporting active public involvement in the NHS, public health and social care research in England) as:

*An active partnership between the public and researchers in the research process, rather than the use of people as the 'subjects' of research. Active involvement may take the form of consultation, collaboration or user control. Many people define public involvement in research as doing research 'with' or 'by' the public, rather than 'to', 'about' or 'for' the public. INVOLVE (2011)*

Despite this description the meaning of public involvement in health research is not straightforward. However, for the present I am using the term to describe a situation where members of the public, who are most likely (but not exclusively) to be patients or other users of health services, assist researchers in the prioritisation, design and conduct of health research studies including helping with dissemination and implementation. I am using the term 'researcher' to describe academics, clinicians and other professional researchers and the term 'research partner' to describe a member of the public involved in a research study.

My interest in this field started in 2001 when I first took part in user-led research as a mental health service user. Subsequently I worked as a user researcher, for example, as a

research assistant at Bristol University, and as chief investigator of a user-led Big Lottery funded project based at Bristol Mind. I am currently a research partner on a National Institute for Health Research (NIHR) Programme Grant focused on suicide prevention and on the Research and Development Committee for the Avon and Wiltshire Mental Health Partnership NHS Trust. Recently I have worked at the University of the West of England in Bristol (UWE) on a project exploring the potential for collaboration between local research active organisations to support public involvement in research, and I have co-chaired the Public Involvement in Research scheme in the Faculty of Health and Life Sciences at UWE. My interest in the area of public involvement in health research has therefore developed through practical experience over some time.

## **BACKGROUND**

Public involvement in health research is government policy. It was first required in the NHS in 1974 with the setting up of Community Health Councils. Despite many changes in the way that public involvement in the NHS has been organised (see House of Commons Health Committee 2007) there has been ongoing government commitment to it. The NHS Act of 2006 (National Archives) included a duty to involve the public in planning, developing and delivering health services commissioned and provided by the NHS. Alongside the development of government policy in relation to public involvement in health in general it has also been established in research. Best Research for Best Health (Department of Health 2006) states that patients and the public must be involved in all stages of the research process, as does the revised Research Governance Framework for Health and Social Care (Department of Health 2005). Some consideration of public involvement is required by the NIHR in all applications for research funding and it is of increasing importance to other health research funders. It is therefore of relevance to many researchers and to the members of the public who work with them.

Although there are clear policy requirements to involve the public in health research, there are different interpretations of its aims and benefits. Some emphasise improvement in the quality of research.

*“No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably makes studies more effective, more credible and often more cost efficient as well.”* Professor Dame Sally Davies, Director General of Research and Development, Department of Health (Foreword to Staley, 2009).

Others describe it as a political process.

*“At its heart, PPI (patients and public involvement) is about empowering individuals and communities, in order that they can play a greater role in shaping health and social care research. In this way PPI aims to democratise health and social care research, to ensure it has maximum health and social benefit.”* (Brett *et al.* 2010, Executive Summary, Background)

As well as this ambiguity there are demands from researchers for more evidence of how public involvement adds value in different research contexts and of its impact, see Boote, Telford and Cooper (2002) and Dewar (2005). An INVOLVE structured literature review (Staley 2009) reports that there are a variety of possible impacts of public involvement in research and a number of factors which influence whether it makes a difference. However, they found limited evidence and inconsistencies in terminology and in describing and reporting on public involvement. Researchers found it difficult to assess the impact of public involvement in research or predict where it would have the greatest effect. Staley (2009) identified that more work is needed to clarify the added value of involvement in different research contexts. A systematic review of patient and public involvement in research was conducted for the UK Clinical Research Collaboration, in which Brett *et al.* (2010) found that the evidence base was complex and in need of significant enhancement. They identified limited conceptualisation and theoretical development and a need for a comprehensive theoretical model. They argue for substantive work to develop instruments that measure impact and identify the importance of context and process. Despite the limitations of the evidence base they identified a range of impacts of involvement in research but recognised that much reporting was poor and that public involvement could be described as a complex intervention. While both Staley (2009) and Brett *et al.* (2010) report evidence of impact in many published articles, both call for further research to improve understanding of public involvement in research in general and about the difference it makes in particular. Most accounts of public involvement are currently provided by the researchers or members of the public reporting on their own involvement activities, and the quality of such self-reporting has been described as variable (both Staley 2009 and Brett *et al.* 2010). Health researchers and members of the public need improved evidence if they are to work together effectively.

While there are suggestions that the evidence about public involvement would be improved by measurement, particularly measurement of impact, it does not seem clear what to measure. Using an ethnographic approach is exploratory and provides an in-depth description utilising data from different sources. This offers a way of engaging with the complexities of public involvement in research and has the potential of identifying

what the important factors are and how they interact in each setting. Fudge, Wolfe and McKeivitt (2008) successfully undertook an ethnographic study of user involvement in health service development. An ethnographic approach aims to provide rich, holistic insights into people's views and actions as well as the nature of the location they inhabit (Reeves *et al.* 2008). It is important to observe what happens as well as collect accounts of public involvement in research. Pope and Mays (2009) suggest that qualitative research needs to do more than taking talk at face value, and that observation is needed to see what people really do, not just what they say they do, Lambert and McKeivitt (2002) agree. Silverman (2005) also emphasises the importance of collection of data in naturally occurring situations. Argyris and Schön (1974) suggest that there are differences between 'espoused' theories and 'theories in use'; my experience suggests that this might be the case in public involvement in research. Being able to look at both actions and accounts is important in public involvement because it is supported by government policy and research funders but not necessarily by all health researchers, and because power is unequally distributed between researchers and research partners. For these reasons, the ethnographic approach offers a fruitful way of investigating public involvement in research.

### **AIM OF THE PROJECT**

This research project aims to describe and make sense of what is going on when the public are involved in three health research studies. This research project also has the purpose of supporting the development of my skills as a qualitative researcher.

### **Research questions:**

1. What do researchers and research partners do when they work together in research studies?

This includes a focus on how, when, where and why they work together, whether there are observable effects and how the context of the study has an influence.

2. How do researchers and research partners describe the experience of working together?

This includes a focus on what has been done, where, when and how, including emotional responses, motivation for involvement, perceptions of what difference it has made and of the effect of context. In addition, I am interested in whether accounts of involvement given by researchers and research partners differ and how.

3. How does public involvement in research get written about in research related documents?

This includes a focus on how such writing relates to observations and accounts of practice.

4. Do contextual factors have an effect on public involvement?

If so, to what extent and how?

5. What is the relationship between observed practice, accounts (including written accounts) of public involvement and contextual factors within one study?

6. What are the similarities and differences between data collected about public involvement in the three studies?

These research questions represent a starting point for my inquiry.

### **RESEARCH DESIGN**

A number of possible qualitative approaches were considered for this project. I have decided to take an ethnographic approach because it is exploratory and can provide a rich description of public involvement in research. I will use this approach to understand what was done, where and when, by whom and with what effects in relation to public involvement within each health research study. This will help to make sense of what is happening and identify what factors are most important and how different factors interact. This research design is well suited to understanding complex and poorly understood interventions like public involvement in research.

This project will be located within the approach to research where knowledge of the world is intentionally constituted through lived experience, in other words, socially constructed (Crotty 1998). This approach fits the project because it seeks to understand how actors co-create a particular social reality, that of public involvement, in a particular research context. Such an epistemology suggests that the researcher and the phenomena being explored are inseparable and that meanings will be interpreted in the light of lived experience. Such a stance makes it important to critically reflect on the understandings, preconceptions and actions that I as the researcher bring to the project, and to actively explore different understandings.



## **Sample**

Three health research studies involving members of the public will be purposively chosen to be varied. Studies will vary by a number of possible factors: subject area, study characteristics and design, context, and approach to public involvement.

Three have been chosen as achievable within the context of a doctoral research project and as a reasonable compromise between breadth and depth. Similarities and differences between public involvement in the three studies will be described. Experienced research partners and researchers who are members of an Advisory Group will provide advice on the sample alongside supervisors.

As the policy jurisdiction for the NIHR is England the project will draw its sample from research studies taking place in England. Studies will be taking place in NHS trusts or universities, potentially including studies run in partnership between such organisations.

INVOLVE describes three forms of public involvement, consultation, collaboration and user control. This project will potentially focus on two of these forms, consultation and collaboration. However, it may be that studies which only consult members of the public would have insufficient public involvement to warrant inclusion in my project. It is possible, therefore, that this project will only explore public involvement where researchers and research partners are working collaboratively. While the third form, user control, has the highest level of involvement there are relatively few user controlled studies; there is also a recent publication on user controlled research (Faulkner 2010). My focus is on how researchers and research partners work together in more conventional research settings.

## **Inclusion and exclusion criteria**

Included health research studies will have involved research partners in some part/s of the research process. Studies may be at various stages but will not be completed. Initial discussions with researchers will determine whether sufficient public involvement is taking place to warrant inclusion. These discussions will take place with researchers because they can be identified and contacted, but research studies will only be included if all research partners agree to participate in the project. All potential participants will be adults with the capacity to consent.

This project will exclude health research studies recruiting children and young people; studies where research partners do not agree to take part; studies that are completed;

and studies where public involvement has already been the focus of publication. Health research studies that have not yet been funded will also be excluded. While it may be important to reflect on involvement in study design before funding has been gained, as a study may not be funded it is unlikely that sufficient public involvement would take place only at the design stage to warrant inclusion in this project. Given the nature of data collection some health research studies may be excluded because they are geographically inaccessible.

#### **Identification of participants:**

The unit of participation in my project is the research study. Identification of studies will take place through local and regional contacts, by accessing the INVOLVE database of research projects involving research partners (INVOLVE 2004), and potentially through the NIHR Central Commissioning Facility (CCF) and the NIHR Evaluation, Trials and Coordinating Centre (NETSCC).

Within each study possible participants will be identified in initial discussions with the chief investigator. The exact number and type of participants will depend on the nature of each research study; however, participants will include researchers, research managers, and other staff working on a research study as well as research partners. Other staff might include administrative staff and staff from NIHR research networks who support the study in some way.

It is possible that observation may include observation of data being collected by researchers and/or research partners from their own study's participants. The justification for such observations would be that research partners are involved in the collection of data in a study, or that research partners had made contributions to the research study which might be having some observable effect on data collection from study participants. It may also be important to observe the collection of data within a research study in order to have a fuller understanding of the study. Such observations would only be made after careful consideration and with the agreement of the chief investigator, researchers and research partners and after discussion with my supervisors.

It is clear that in my project identification of potential participants may not be a straightforward or one-off activity. Wherever possible if additional participants are identified prior written informed consent will be sought.

**Recruitment:**

The aim is to recruit three health research studies. The recruitment process will start once the project has ethical approval, in the summer of 2011. Having identified potential studies for inclusion there will be quite a lengthy recruitment process. There are three sub-groups of participants in my project and each of these groups would be recruited in a different way.

**Group 1 - Recruitment of identifiable researchers, research managers, other staff and research partners**

This is the primary participant group; all potential participants in this group will be adults with the capacity to consent. The first person to be approached would be the chief investigator of the identified study, information about the project and its approach would be provided and discussed. If the chief investigator were interested in the project and willing to consider taking part, discussions would then be held to identify everyone who should be approached, and to consider how best to provide information to the researchers, research managers and other staff working on the study. The chief investigator will be asked to discuss participation in my project with all research team members, including research partners, to find out whether they are willing to be approached about my project. If they are willing an opportunity to provide information will be arranged. All researchers, research managers, other identified staff and research partners will need to be informed and be willing to take part. The process of providing information might take place one to one or in a group at their choice and convenience. A flow chart of recruitment of Group 1 participants is provided in Appendix 1.

All potential participants will have the opportunity to talk to me in person or on the telephone to get further information about the project before they consent to take part.

**Group 2 - Recruitment of people who are providing data for one of the participating research studies**

Whether or not such recruitment is desirable or possible would be discussed with the chief investigator and my supervisors in advance. Researchers in Group 1 would identify and approach Group 2 participants on my behalf; up to five people in each research study would be recruited.

### **Group 3 - Recruitment of 'ad hoc' participants**

As the ethnographic approach may include spending time in a research office and informal observation and shadowing, it will be impossible to identify every possible participant in advance. Ad hoc participants might include staff who share office space with participants in Group 1, or who take part in some research or institutional activity with participants in Group 1 which I observe. They may also be encountered while shadowing a participant from Group 1 or attend a study meeting on a one-off or occasional basis.

#### **Consent:**

Consenting to take part in my project does not imply that all research activities will be accessible to me. When information is provided about the project I will make it clear that participants are not writing a 'blank cheque' regarding access; access will be negotiated and renegotiated over the period of time that data is being collected. I will be sensitive to the work of the research study and to all participants; it will be clear that I can be asked to stop an observation or to stop taking notes or recording when necessary.

The consent process will vary according to the groups described above.

#### **Group 1**

Written and verbal information will be available to all potential participants in Group 1. I will offer to attend research study meetings, or to arrange a meeting specifically to discuss my project. I will discuss the best way of providing information about my project and its approach with the chief investigator and other researchers in initial contacts. Potential participants will have an opportunity to ask questions when information is provided and again when the consent form is completed. Potential participants will have an opportunity to reflect on whether or not they are willing to take part. The project information sheet contains information about how participants can complain about the conduct of my project. Participants will keep one signed copy of the consent form and I will keep the other.

If any individual member of a research team in Group 1 does not give consent then discussion will be held with the chief investigator as to whether or not the project can go ahead. If such a member does not have a central role in the research team the project may be able to go ahead within agreed limits, for example, the agreement that no audio-recording would be made of any events at which they are present, and that they will not

be asked to participate in an in-depth interview. Whether or not my project could go ahead and on what basis would need to be carefully negotiated. This arrangement would not apply should any research partner not give consent.

All research partners will have the opportunity to meet me to discuss the project and ask questions. The only exception would be if research partners were linked to the research study from a geographically remote location; in such cases a telephone conversation would be offered instead. All research partners will have a week over which to reflect on whether or not they are willing to take part in my project.

There are two information sheets for participants from Group 1, one for members of the public (Information Sheet – members of the public, version 3.0, 20 December 2011) and one for researchers and research managers (Information Sheet – researchers, version 3.0, 20 December 2011). These information sheets provide the same information with slightly different wording. There is one consent form for people in this group (Consent Form, version 3.0, 20 December 2011).

## **Group 2**

Written and verbal information will be provided to all potential participants in Group 2 by a researcher or research partner in a participating study. They will provide information about my project and answer any immediate questions on my behalf. Prior written informed consent for my observation of data collection would be sought on one occasion only. How long potential participants in Group 2 have to reflect on the information before consent is taken will depend on the arrangements applicable within each research study. The project information sheet contains information about how participants can complain about the conduct of my project. Participants will keep one signed copy of the consent form and I will keep the other.

There is a modified (shorter) information sheet and consent form for participants in this group: Information sheet – Group 2, version 2.0, 25 July 2011; Consent form – Group 2, version 3.0, 20 December 2011.

## **Group 3**

I will be introduced to people encountered during observations who do not know who I am or what I am doing. Some people encountered during observations might be identified as Group 3 potential participants by Group 1 participants. Should this happen they will be given verbal information about my project, the information sheet for

researchers, and they will have an opportunity to ask questions about my project. Limited time for reflection will be available. Written consent will be sought from potential Group 3 participants.

If potential Group 3 participants do not consent to take part appropriate action will be considered and agreed in each situation. This might include not audio recording a meeting in which they take part, excluding any data provided by them that is recorded, or stopping an observation. I will be sensitive to the wishes of project participants from Group 1, to the work of the research study and to the situation. My stance will be that data can be collected only in situations where it is clearly agreed. The information sheet for researchers will be used for Group 3 (Information Sheet – researchers, version 3.0, 20 December 2011).

**Withdrawal:**

If a participant decides to withdraw from the project what will happen to their individual data will be agreed when the consent form is signed. The options will be to allow me to use individual data that has already been collected, or for all individual data to be withdrawn. The same clause of the consent form will also indicate what they want to happen to their individual data should they lose capacity and be unable to continue to participate in my project. If a participant decides to withdraw they will have the opportunity to review and change the decision they made about their data at consent.

The information sheets for members of the public and for members of Group 2 make it clear that participants can withdraw at any time and that this will not affect their involvement as a research partner or as a research subject.

**Data collection:**

In this project I plan to collect data in a number of different ways. Data collection from all sources will include a focus on the culture and context in which the research study takes place. Data collection will be conducted over a period of up to eighteen months. Most data will be collected over a period of 12 months, but the period of data collection may extend to eighteen months where public involvement activities are infrequent or to include the collection of additional study documents (perhaps allowing the collection of additional published articles or reports) and to complete follow-up in-depth interviews or discussions about photographs taken if necessary.

## **Observation**

This includes both participant and non-participant observation of the research study.

Exactly who is observed, doing what, where and when will be determined in discussions with participants. Observation would take place of informal and formal research activities which include researchers and research partners and of informal and formal research activities carried out only by researchers (or research partners if applicable).

Observations may include shadowing of researchers and research partners and of some activities that are not research study specific to gain an understanding of the context.

Observations are planned to include the following situations:

- Participant observation of researchers and research partners at work at an agreed time and place.
- Participant observation while shadowing a particular researcher or research partner for an agreed period of time, possibly half a day or a day. Shadowing would involve accompanying the participant in all their activities (with agreement).
- Participant observation in public areas of a NHS trust or university where researchers and research partners are based.
- Non-participant observation of research meetings or other research activities. Such research activities would include both/either researchers and research partners.

All observation is based on the building of relationships with participants and on their willingness to permit access to specific situations. Observations include a variety of possible dimensions: space (physical layout of place), actors (who takes part), activity (a set of related activities that occur), objects (physical things that are present), acts (single actions undertaken), events (activities that people carry out), time, goals and feelings (both felt by the researcher and expressed by those observed).

Field notes will be taken during all observations, and supplementary notes will be made soon after an observation is complete. Supplementary notes will be distinguishable from field notes. Observations will be digitally audio-recorded wherever possible with permission.

## **Interviews**

This includes carrying out at least two, possibly more, in-depth interviews with all researchers in smaller research projects, or a sub-group of researchers in a large research project, and with all research partners. How many and which researchers will be interviewed will be determined in discussions with the chief investigator during the

recruitment process. It is possible that other participants from Group 1 may also be interviewed.

Initial interviews will have a broad focus, asking how a participant came to be working on this study at this time, including relevant personal background and contextual information. Semi-structured questions have been drafted for use in the first health research study. However, given the nature of the ethnographic approach these questions may evolve after use – supplementary questions may be identified and/or some areas of inquiry may be amended. Follow up interviews will focus on emerging project questions and themes. Interviews will take place at a place and time convenient to participants. Each interview will take approximately 45 minutes. All in-depth interviews will be digitally audio-recorded with permission. Research partners will receive out of pocket expenses for attending interviews.

Interviews will be carried out in a number of locations dependent on the participating health research study. Many will take place in university offices or meeting rooms, some interviews may take place in hospital meeting rooms or offices, and occasionally in clinical areas. Interviews with research partners may take place at their home if that is their preference. My director of studies and I will follow UWE Bristol's Safety Guidance Note entitled 'The safety of social researchers' which includes procedures for conducting interviews in participant's homes including carrying a mobile phone and ensuring that a supervisor is aware of my whereabouts.

All interviews will be carried out in private in as quiet a location as possible. I will check whether potential rooms are suitable and book them in advance. I will aim to conduct all interviews in offices or meeting rooms with a closing door. Clinical areas will only be used if appropriate private space which allows confidential discussion is available. If an interview is interrupted it will be temporarily suspended until privacy is restored.

### **Documents**

This includes the collection of research study documents, for example, the funding application, the ethics application, protocol, and any reports or published articles that are available. Documents that provide contextual information about the research study and institution/s in which it takes place would also be identified and collected. Identification of relevant documents will take place in discussions with researchers and research



partners. Part of the reason for extending the data collection period from six to eight months is to allow the collection of the most recently written reports or articles.

Where possible, documents will be collected in a digital form on a memory stick.

Documents collected in this way will be transferred onto UWE computers, memory sticks will only be used to transfer data.

### **Photo elicitation**

I will ask up to four researchers and research partners (two of each) who are willing to take up to 5 photographs on a disposable camera provided by me. Photographs will in some way represent their experience of working on the research study, of public involvement and their emotional responses. I would agree a time over which the photos would be taken with each participant. The camera will be returned to me and I will develop the photos. Photos would then be shared in a one to one meeting with me at which participants would describe why they took the photos and what they mean to them. These meetings will be audio recorded with permission. Meeting would take place at a time and place convenient to the participant.

The aim is to see whether this method of collecting data provides a different type and quality of information. Participants will be offered a copy of the photographs to keep if they wish. Research partners will receive out of pocket expenses to take part in these discussions.

### **Reflexive diary**

A reflexive diary will be kept by me, including ideas, thoughts and feelings that arise in the process of doing this project. It will be important to reflect on how my presence and explicit focus on public involvement in research might be affecting what happens over the time that I am collecting data as well as on the extent to which I am seen as an 'expert' on public involvement, and checking up on/evaluating how public involvement is being done.

### **Storage and use of data**

Participant and non-participant observations will be audio recorded with a digital audio device with permission, as will in-depth interviews and discussions about photographs. Audio files will be saved on password protected University computers. Transcription of audio files will only be done by me. Written field notes will be made during observations and supplementary notes will be added soon afterwards, field notes and supplementary

notes will be typed up and saved on password protected University computers. Transcripts of observations and interviews will be anonymised; reference in transcripts to identifiable people and to an identifiable research study will be removed. Direct quotes from transcriptions will be used in publications and oral presentations. Quotes will be anonymised and identified by a pseudonym, research studies will also be given a pseudonym and identifying details will be changed.

Contact details will be collected for research partners in order to conduct in-depth interviews and discussions about photographs. Personal data will be stored separately from all other data in a locked filing cabinet at Glenside Campus, UWE. Personal data will be stored and accessed for up to 1 year after completion of the project and then disposed of securely. Paper and electronic media containing identifiable information (such as consent forms and audio files) will be stored securely in locked filing cabinets or on secure University computers. Manual files will be stored in a secure locked filing cabinet at UWE. Data will be securely stored for six years and then destroyed.

Photographs will be taken on disposable cameras provided by me. Copies of photographs will be stored digitally on password protected University computers. Photos may be included in publications. Photos will be anonymised by obscuring any identifying details by pixilation. Documents will be collected in digital form if possible, if not they will be collected on paper. Documents will be saved onto a UWE memory stick only in the period of transfer from a research study site to UWE. They will be deleted from the memory stick after transfer and stored on a password protected University computer.

Participants will be asked to check the accuracy of transcripts of audio recordings of data that they have provided. Following audio recorded interviews and discussions of photographs participants will be asked if they are willing to check their own anonymised transcripts for accuracy. Participants will also have the opportunity to add further comments on these transcripts if they wish. Comments will be included as additional data. Audio recordings will be typed up verbatim with agreed conventions, for example showing where the recording is unclear or where two or more people talk at the same time in a meeting. Pauses and intonation will be included. Transcripts will be as detailed as possible within the time constraints of the project.

### **Confidentiality**

All participants will be given verbal and written information explaining arrangements for the secure storage of data. Participants' names and contact details will be stored

separately from data in a locked cabinet. Personal data will be stored and accessed for up to 1 year after completion of the project and then disposed of securely. Personal data will only be accessible by me and my director of studies. All data collected will be treated in strict confidence. All transcripts of recorded data will be anonymised and will be stored securely. Anonymised data will be seen by me and study supervisors/advisors. Real names and identifying details will not be used in reports or published materials. Anything seen or heard while I am observing participants will be treated in strict confidence. No identifiable information will be discussed with anyone outside my project.

When data from different participants in one study are linked together in writing participants will have the opportunity to check and amend what is being written about them in advance. I will do this because it may be possible for people working together to identify each other even if data is anonymised. I will use the data only to write my PhD thesis and for dissemination in articles for publication in journals and in presentations.

### **Implications of study design**

It is clear that an ethnographic approach implies a somewhat flexible research design and a focus on whatever data throw light on the emerging focus of inquiry. Initial interests and questions are likely to be refined over the course of the project. Data collection is relatively unstructured, so it is not necessarily clear at the outset where and when observations should take place or who needs to be shadowed or interviewed. Some data collection is informal and opportunistic. Such an approach makes it difficult to describe the project with precision to potential participants. This problem can be mitigated by explaining the approach in advance, including the somewhat flexible design, and by describing the range of possible ways that data might be collected. Participants are also protected in the sense that access is constantly negotiated and renegotiated during the time that data is collected. The evolution of the research design will be discussed with my supervisors and advisors.

### **Risks, burdens and benefits**

There is little risk to any participant who takes part in this research project. Research partners will not be asked about their experiences of receiving health care, but such personal experiences might have motivated involvement in research, and therefore be shared. If such experiences are shared they will be treated with sensitivity; as will any information shared of a more personal nature. It is possible that describing experiences of

involvement informally, in in-depth interviews, or while discussing photographs, might be upsetting if involvement has been a difficult experience.

Should a participant become distressed during an interview or in a discussion about photographs the following procedure will be followed:

- i) A sheet providing information about possible sources of support has been produced; see Sources of support (Version 1 - 23 September 2011). It provides information about generic support services including the Samaritans which is available 24 hours a day and some support services linked to health areas which are the focus of potential participating research studies for the project. This sheet of information will be given to any participant who gets distressed during data collection.
- ii) Should a participant get distressed I will ask them if they wish to stop the interview or if they need to take a break. If they wish to stop the interview I will check whether or not they are willing to meet me again to complete the interview and if it is OK for me to contact them to arrange an alternative date. If they wish to take a break this will be accommodated and the interview will continue when they feel ready. I will ask participants if they would like to get a drink or take a walk away from the interview location while they take a break.
- iii) I will ask the participant if they think they need to consider getting some support for their distress or whether they wish to cope with it in their own way.
- iv) If they say that they might need some support I will offer the written information described in point i) which will include sources that might be helpful and we will discuss whether they can identify alternative sources of support which they might use.

There is a risk that participants may identify each other when I link data provided by different participants within one study. This may happen despite data being anonymised. This risk will be addressed by participants having the opportunity to check and amend what is being written about them when accounts are linked together.

The work of an included health research study (particularly in relation to a study's own participants and its research partners) may include risks or raise sensitive or embarrassing issues which I might observe and witness. I will make myself available for any debriefing or other action if requested by researchers or research partners following such a situation and will reflect on such situations within the context of my project. All participants will be protected by the ethical approval and approach agreed for their study.

There is relatively little risk to me in doing this project. Where possible in-depth interviews will not be conducted in participants' homes but in an institutional setting. Interviews will only be conducted at the home of a participant already known to me. UWE has a safety policy which will be followed by me and my director of studies. The

policy includes carrying a mobile phone and ensuring that a supervisor is aware of my whereabouts. It is possible that ongoing contact with the work of a research study could be distressing or that particular events may be distressing, challenging or problematic. I will record and reflect on any such situations and discuss them with my supervisors.

The main burden of this project is in relation to the potentially intrusive nature of the ethnographic approach on the work of a research study. This will be minimised by being sensitive to the needs of all participants, to the work of the study and through ongoing negotiation and renegotiation of access with researchers and research partners. Although this approach may be intrusive to some extent, it offers the possibility of understanding the complexities of public involvement in research in context in a way that is not offered by other qualitative approaches. I feel the possible burden can therefore be justified.

Being observed may feel uncomfortable or intrusive, particularly in some more sensitive or demanding situations. At first participants may be very conscious of being audio-recorded and of me taking field notes. However, the reason for this approach will be explained before consent is obtained and it is hoped that being observed will become easier as participants build a relationship with me and get used to my presence. Audio-recording and note taking will be stopped for periods during observation if requested or I will leave a situation. Participants will be clear that all data collected will be confidential and that I will respect the confidentiality of any sensitive or personal information that is discussed when I am present.

Taking part in interviews may be time consuming. Any inconvenience will be minimised by informing participants how long interviews are likely to take, and by arranging them at a convenient time and place. Interviews will be postponed and rearranged if necessary.

Taking photographs about public involvement and the research study may be time consuming, but participants can choose whether or not they take part in this part of the project. Meetings to share photographs and discuss them will take place at a time and place convenient to the participant.

The opportunity to reflect on public involvement may be helpful and enjoyable for participants. If study participants are interested in finding out more about this field I will be able to provide links to sources of guidance and information about public involvement in research, and to local, regional and national networks.

### **Research governance and monitoring:**

The project will be conducted in compliance with the Research Governance Framework for Health and Social Care and Good Clinical Practice. The project will be subject to established arrangements for research governance and monitoring at UWE. My work on the project will be subject to feedback from my supervisors and members of the Advisory Group.

### **Analysis of data**

Processing and transcription of study data will take place alongside data collection. Digital audio-recordings of observations, in-depth interviews and discussions about photographs will be transcribed and anonymised by the researcher. Field notes will be reviewed as soon as possible after data collection to add supplementary information from memory (which will be identifiably different from the original notes). Field notes will be typed up and anonymised by the researcher to enable electronic input for analysis. Copies of photographs will be stored electronically. All transcripts, field notes, documents and photographs will be imported into Nvivo. Analysis of data will be supported by the use of Nvivo to speed up the routine tasks of sorting and searching through large quantities of qualitative data.

Analysis of data will be carried out throughout the data collection process as well as after all data is collected. As data collection proceeds it will become more strategic as significant themes are identified. Analysis will be inductive and iterative, aiming to interpret the meaning and functions of actions and to put forward tentative theoretical explanations of public involvement. Data analysis of observations, interviews and documents will be broadly thematic, focusing on the content of the data and including the processes/interactions in different settings where appropriate. Initial coding will be open, in vivo codes will be identified which arise directly from the data, from the voices of the participants, which are immediate and alive. This will be followed by axial coding to connect in vivo codes in the data, generating in vitro codes using the constant comparison method. Grounded theory will be used to develop concepts within the data.

Data from the different sources (observation, interviews, documents, photographs) will be used to generate a more comprehensive understanding of public involvement within each health research study. Observed behaviour will be compared with verbal accounts of public involvement from interviews, and with written accounts in study documents. Documents will be analysed with a concern for the process through which texts depict

'reality' rather than with a concern about whether texts contain true or false statements. Reflection on the collection of data, researcher ideas and experiences will be included in the analysis. Similarities and differences in public involvement across the three studies will be compared. Findings will be written up as a verbal description and explanation.

The researcher will use Silverman's (2003) criteria to address validity issues in the analysis. This includes consideration of the refutability principle, using the constant comparative method, by comprehensive data treatment, by deviant case analysis and by using appropriate tabulations. Silverman suggests that to allow others to take a view on reliability researchers must document procedures and demonstrate that categories are used consistently; this will include the use of low-inference descriptors and providing readers with long data extracts. In addition, clear field note conventions will be used and some anonymised data will be coded by supervisors and members of the Advisory Group to test for inter-coder agreement. Transcripts will be detailed and verbatim to reveal the more subtle features in talk.

### **Advisory Group**

This project will include the recruitment of a small Advisory Group which will include no more than four members excluding me. This group will include two research partners with experience of being involved in health research, a research manager and a researcher.

This group will meet twice a year and members will be asked to be available for informal contact and advice. The aim of the group is to make sure I consider the views of people with relevant experience while I am doing my project, the precise role of the group will be agreed with group members. Research partners will have the opportunity to be paid for contributing to the Advisory Group.

The Advisory Group can help me refine the design of my study and think through options for data collection. Members will be asked to take part in pilot interviews and provide feedback. Members may review some study data to see whether they identify similar themes and how they might name emerging themes. Members will also be involved in dissemination of study findings if possible.

### **Timetable**

The aim is to recruit three research studies and start data collection at two/three monthly intervals from September 2011. Data collection should be complete by May 2013. Some

data analysis will take place while data is being collected, and data analysis will be completed by July 2013. My thesis should be submitted in the Autumn of 2013.

### **Dissemination**

A short and accessible report of the project will be produced for researchers and research partners who have taken part, and for wider dissemination, for example through INVOLVE. Project findings will also be presented to project participants if they wish. In addition to the production of the thesis I aim to publish at least two peer-reviewed articles related to the project and to present findings at conferences and workshops where possible.

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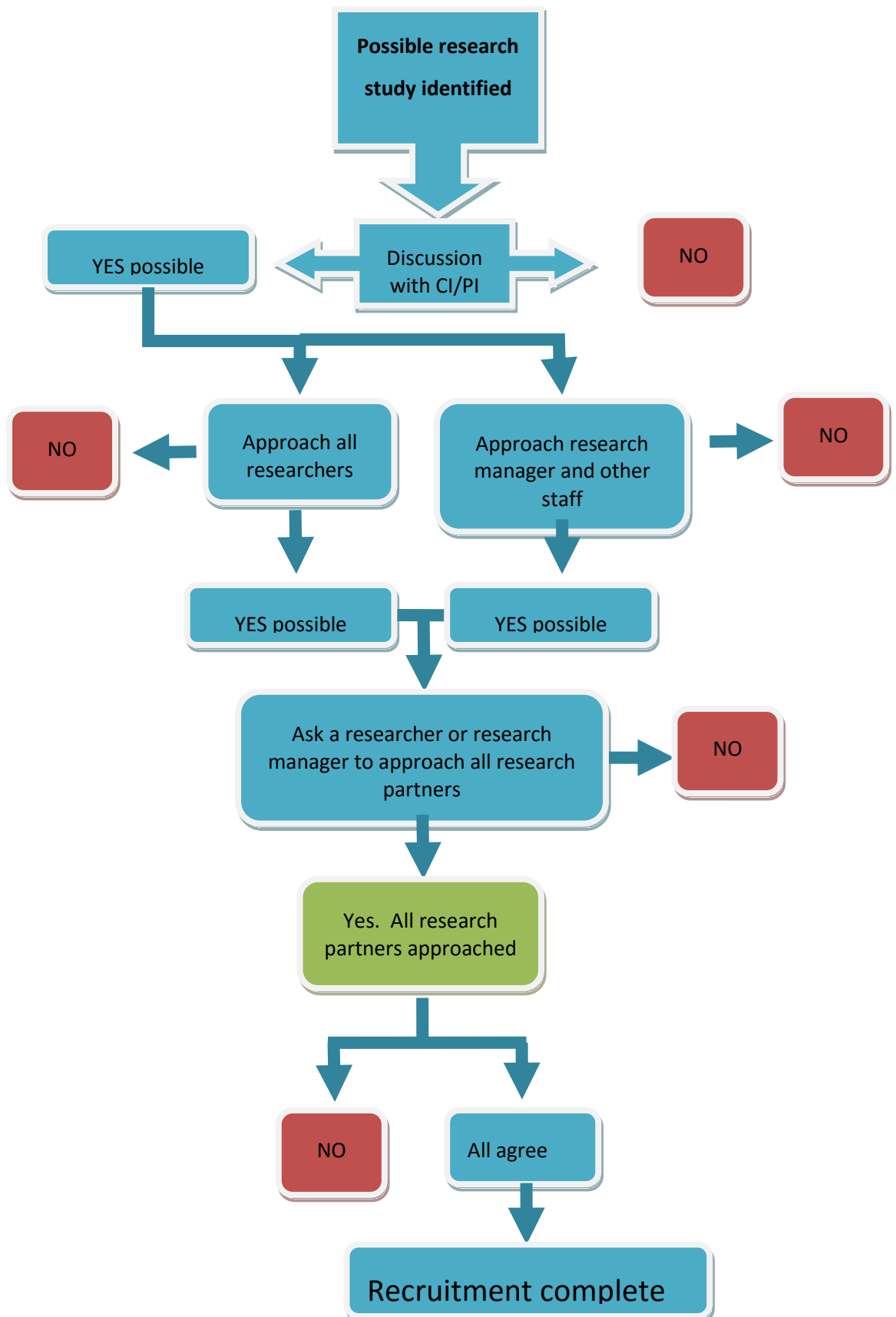
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APPENDIX 1 – Recruitment flow chart for Group 1 participants



## Appendix 11: Information sheet for members of the public



University of the West of England  
Faculty of Health and Life Sciences  
Blue Lodge, Glenside Campus  
Blackberry Hill  
Bristol BS16 1DD

### Information sheet for members of the public

I am inviting you to take part in my research project. Before you decide if you want to take part it is important for you to understand why the project is being done and what it would involve for you. I will go through this information sheet with you and answer any questions you have. This should take approximately 10 minutes. Let me know if you would like more information, do ask me if anything is not clear. Please take your time to decide whether you wish to take part or not and talk to others about my project if you wish.

Thank you. Rosie Davies

**Project title:** What is going on in public involvement in health research? An ethnographic exploration of the aims, processes and outcomes of public involvement in three health research studies.

#### What is the purpose of the project?

My project aims to find out about your involvement in research. I want to describe and make sense of what happens when members of the public like you are involved in health research studies. I would like to talk to members of the public, to professional researchers and other people working in three research studies. The project will take place over 3 years, finishing in September 2013. As a member of the public involved in a research study you might be helping researchers in a variety of ways. This could include planning a study or making sure that written information is easy for research participants to understand. There is government policy which encourages professional researchers to involve members of the public in research studies.

I have three main questions:

1. What do researchers and members of the public do when they work together in research studies and what difference does it make?
2. How do researchers and members of the public describe the experience of working together and what difference it makes? Do their accounts differ?
3. How does public involvement in research get written about in research related documents?

The information in this box is adapted from **INVOLVE** which is a national advisory group supporting greater public involvement in NHS, public health and social care research.

The **public** includes, for example,

- patients and potential patients
- people who use health services
- parents, relatives, guardians
- disabled people
- organisations that represent people who use services.

**Public involvement** means an active partnership between the public and researchers in the research process, rather than the use of people as the 'subjects' of research. Many people define public involvement in research as doing research 'with' the public, rather than 'to', 'about' or 'for' the public.

More information is available from:

[http://www.invo.org.uk/About\\_Us.asp](http://www.invo.org.uk/About_Us.asp)

This project is the focus of my work as a doctoral student at the University of the West of England.

### **Why have you been invited?**

You are being invited to take part because you are already involved in a research study that I would like to investigate. I would like to find out about what you have done to help professional researchers in the study, what difference you make and what it has been like to be involved. In my project I sometimes refer to members of the public as research partners.

### **Do you have to take part?**

It is up to you to decide whether or not to take part. I will describe my project and go through the information sheet. If you agree to take part you will be asked to sign a consent form.

You are free to withdraw at any time without giving a reason. If you decide to withdraw from my project this will not affect your involvement in the health research study you are working on in any way. If you decide to withdraw for any reason, or something happens and you can no longer take part, I would still like to use any information you have already given me for my project. However, you may not agree with this. If you wish I will not use any individual information that you have provided before you withdraw. Your decision about this will be recorded on the consent form.

### **What will you have to do if you take part?**

If you agree to take part in my project I will ask you to give me information in a number of ways over several months (up to a maximum of eighteen months). My aim is to get an in-depth understanding of the research study and of the public involvement taking place; this includes getting to know the people who are involved. In order to do this I would like to do a number of different things. This includes observing what happens, interviewing people taking part, asking you to take photographs (if you are interested) and also collecting documents about the research study.

### **Being observed**

If you agree to be observed in the ways described below you are not writing a 'blank cheque' regarding access. My observation of any situation is open to negotiation at all times.

1. I would like to observe you working on the research study with professional researchers informally and/or shadowing you when you are working on the study. This means I would take part in informal activities with you and professional researchers, or spend some time with you specifically while you are working on the study. We would have informal conversations while I am with you, but I would aim not to be too intrusive or to interrupt what you are doing. While I am with you I would like to take some notes as I go along so that I can remember what happened, and also to make audio recordings of what happens and of our conversations when this is acceptable to you. I would be guided by you and by the professional researchers and anyone else involved as to what feels OK in any situation and when my presence is too intrusive. If you agree to be observed we will discuss and agree what is appropriate in each situation, you will not have given me unlimited access to your activities. I would like to make observations so I can get a good sense of what you and the professional researchers are doing, so that I can understand more about the research study more generally and the part of the National Health Service or university in which it is taking place.

2. I would sometimes like to observe you working on the research study without taking part. I would like to come along to research meetings and other more 'formal' activities that you take part in with professional researchers. If you agree to be observed we will discuss and agree which activities can be observed in this way, you will not have given me unlimited access. With permission I will record what happens on a digital recorder and I will also make notes about what I see and hear. I will not take part in the activity myself; I will just record and observe what happens. After the meeting or activity I will type up the recording of what happened and my handwritten notes.

I might also observe you collecting data from research participants in the study you are working on if you are involved in this process. Whether or not this is possible will be agreed with the chief investigator in advance, and additional informed consent would be requested. Such observation would be conducted with particular sensitivity and only with express agreement of all concerned.

If any observations include people who do not know who I am or what I am doing I will be introduced and explain what I am doing. If anyone is identified while an observation is being conducted who might contribute to my project verbal information about my project will be provided, with a written information sheet and I will answer any questions they may have. I will seek written consent from them to collect data for my project.

### **Being interviewed**

3. I would like to meet with you at least twice over the time I am collecting information about the research study. The interviews will only include you and me. An interview is likely to take about 45 minutes; it will not go on longer than an hour. The interviews will take place somewhere convenient for you at a time you choose. This could be where the research study takes place, or at some other quiet, convenient and private location agreed between us in advance. You will be free to end or leave the interview whenever you wish. I would like to digitally record the interview and I will ask your permission to do this at the start of the interview. After the interview I will type up the recording of what was said.

### **Taking some photographs**

4. If you are interested I would like you to take a few photographs (not more than 5) on a disposable camera which I will give you. The aim is for you to take pictures that in some way represent your experience of what it is like to be involved in the study and/or your feelings about being involved. After you have taken the photos I will ask you to return the camera to me. I will develop the photos and send them to you. We will arrange a time to meet at your convenience so that we can look at the photos together and you can tell me a bit about why you took them and what they mean to you. You can keep a copy of the photos if you wish. With your permission I would like to digitally record this discussion. After the discussion I will type up the recording of what was said.

### **Collecting documents about the study**

5. I would like to collect copies of study documents for my project to see whether and how public involvement is described. This might include what was written to apply for funding, the study protocol and any other documents that might be relevant including published articles if they are available. I would also like to collect documents which

provide contextual information about the research study and the institution/s in which it is taking place. I will ask you or the professional researchers to provide me with copies.

### **Expenses and payments**

I will pay any reasonable travel and carer expenses for you to take part in the interviews and to discuss the photos. I will not be able to offer you payment to take part in my project.

### **What do you have to do?**

When I come to **observe** you informally or shadow you I would like you to let me accompany you and to talk to me about what you are doing when this is appropriate. I would try not to disrupt your work and I will stop observing you at any time you find me too intrusive. When I observe a meeting or other more 'formal' activities that you take part in I will not take part and I hope you will carry on as you would if I were not there as much as possible.

In the **interviews** I will ask you about your experience of being involved with the professional researchers. This might include how you got involved in the first place, what sorts of things you have done, what you expected before you started and how it has actually worked out in practice. I would also like to ask you what difference you have made by being involved. You will have a chance to tell me about anything you think is relevant. You are free to respond to my questions in any way you like.

It is up to you what **photographs** you take with the disposable camera I give you. The aim is for you to take photos that in some way represent your experience of being involved in the study and/or how you feel about it. After you take the photos I will ask you to return the camera to me. We will agree to meet at your convenience and look at the photos together so that you can tell me a bit about why you took them and what they mean to you. You can keep a copy of the photos if you wish.

I would like to take notes when I observe you informally and digitally record what happens when this feels OK. I would like to take notes and digitally record observations of meetings and other more 'formal' research activities. I would like to digitally record the interviews and discussion about the photos. All recording will take place with your permission. Taking notes and recording will be done so that I have an accurate record of what happened.

When I collect **documents** from you or one of the professional researchers I will need either a paper copy of the document or, ideally, a digital copy which I would put on a computer memory stick. I will transfer any digital documents onto a password protected computer as soon as possible. Documents will not be kept on a memory stick after transfer.

When I have typed up transcripts of observations, interviews or discussions about photographs that you have contributed to you will have the opportunity to check my transcripts for accuracy and make any further comments on them if you wish.

### **What are the possible disadvantages or risks of taking part?**

I do not think there will be any risks in taking part in my project; however, it is possible that you might find talking about your experiences of being involved with the professional researchers a bit distressing if it has been a difficult experience for you. If this happens our contact can stop if you wish or you can take a break. If you would prefer to stop the interview I will check whether or not you are willing for me to contact you to see how you feel about meeting again to complete the interview. I will check whether you have any support needs and, if so, how they might be met. I will provide some written information about possible sources of support.

It is possible that being observed might feel intrusive, awkward or uncomfortable. I will be as sensitive as possible to you and to the work of the research study and will stop observing if you feel it is too intrusive or inappropriate. I hope that as you get to know me and get used to my presence you will feel more at ease.

### **What are the possible benefits of taking part?**

You may find that talking about what you are doing, your experiences and views and sharing your photos is interesting and gives you an opportunity to reflect on what being involved in health research has been like for you. I hope you will enjoy taking part.

### **What happens when the project stops?**

If the project stops early for any reason I will explain this to you.

### **What if something goes wrong?**

If you have any complaints about me and what I am doing or are unhappy about any aspect of taking part in my project you can contact me or my supervisor, Dr David Evans at the University of the West of England (UWE). His contact details are at the end of this information sheet. All complaints will be handled sensitively and be looked into by UWE, in line with UWE's complaints procedure. You will be kept informed during this process.

In addition, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated while you take part in my project, the normal National Health Service complaints mechanisms will also be available to you.

### **Will taking part in this project be kept confidential?**

Yes, all the information I collect from you will be treated in strict confidence and anything I hear or see while I am observing you will be treated in strict confidence and will not be discussed with anyone outside my project.

All information collected will be anonymised and will be stored securely. The information will only be seen by me and my supervisors/advisors. Your name and contact details will be kept separately in a locked filing cabinet. Identifiable personal information will be kept up to one year after the project ends and will be disposed of securely. No details that would identify you, the professional researchers or the study will be used when I write up the project. I may change names and some identifying details in my thesis. I may include quotes from what you say, but I will not identify who said them. I may include your photos in publications; any identifying details will be obscured.

When I write about public involvement in a research study linking together information provided by different people you will be able to read and amend what I say before it is finalised. This is to make sure you feel comfortable about what I write. I will do this because it may be possible for people working together to identify each other even if information is anonymised.

I will use the information to write my PhD thesis, when I write articles for publication in journals and when I give presentations about my project. All information will be stored securely on University computers, it will be kept for six years and then disposed of securely.

### **What will happen to the findings from the project?**

Towards the end of my project I will write up my findings in a short report which I will send to you and offer to come and make a presentation anyone who has taken part from the research study. I will use the information I collect to write my PhD thesis, in articles for publication in academic journals and when I give presentations about what I have found out. You will not be identified in any report or publication unless you give me your consent.

### **Who is organising and funding the project?**

I am organising the project as a doctoral student in the Faculty of Health and Life Sciences at the University of the West of England (UWE) Bristol. I am funded by UWE in my studies. I have a supervision team of three people; Dr David Evans is my Director of Studies.

### **Who has reviewed the project?**

All research in the NHS is looked at by an independent group of people. This project has been reviewed by an NHS Research Ethics Committee. The research has also been reviewed by my supervision team, by the Faculty Research Committee and the Faculty Ethics Committee at UWE.

### **Contact information**

Further information is available from:

Rosie Davies, Blue Lodge, Glenside Campus, University of the West of England, Blackberry Hill, Bristol BS16 1DD. Tel: 0117 328 8796 (shared line).

Email: [Rosemary3.Davies@uwe.ac.uk](mailto:Rosemary3.Davies@uwe.ac.uk)

Professor David Evans, Director of Studies, Room 2G07, Glenside Campus, University of the West of England, Blackberry Hill, Bristol BS16 1DD. Tel: 0117 328 8750.

Email: [David9.Evans@uwe.ac.uk](mailto:David9.Evans@uwe.ac.uk)

You can keep this information sheet about the project. If you decide to take part in my project or if you want any further information please let me know and I will get in contact with you. If you agree to take part you will be asked to sign that you have read and understood this information and that you are happy to take part in my project. You will be given a copy of the signed consent form to keep.

**Thank you for taking the time to read this information**

**Rosie Davies**



## Appendix 12: Information sheet for researchers and research managers



University of the  
West of England

University of the West of England  
Faculty of Health and Life Sciences  
Blue Lodge, Glenside Campus  
Blackberry Hill  
Bristol BS16 1DD

### Information sheet for researchers and research managers

I am inviting you to take part in my research project. Before you decide if you want to take part it is important for you to understand why the project is being done and what it would involve for you. I will go through the information sheet with you and answer any questions you have. This should take approximately 10 minutes. Let me know if you would like more information, do ask me if anything is not clear. Please take your time to decide whether you wish to take part or not and talk to others about my project if you wish. Thank you. Rosie Davies

**Project title: What is going on in public involvement in health research? An ethnographic exploration of the aims, processes and outcomes of public involvement in three health research studies.**

#### What is the purpose of the project?

The project aims to describe and make sense of what happens when members of the public are involved in health research studies. I would like to talk to members of the public, professional researchers, research managers and other staff working on three research studies. The project will take place over 3 years, finishing in September 2013.

Members of the public involved in a research study might be helping in a variety of ways. This could include study design, choice of outcome measures or making written information accessible for research participants. There is government policy which encourages public involvement throughout the research process. In my project members of the public who are involved are described as research partners.

I have three main research questions:

4. What do researchers and research partners do when they work together in research studies and what difference does it make?
5. How do researchers and research partners describe the experience of working together and what difference it makes? Do their accounts differ?
6. How does public involvement in research get written about in research related documents?

The information in this box is adapted from **INVOLVE** which is a national advisory group supporting greater public involvement in NHS, public health and social care research.

The **public** includes, for example

- patients and potential patients
- people who use health services
- parents, relatives, guardians
- disabled people
- organisations that represent people who use services.

**Public involvement** means an active partnership between the public and researchers in the research process, rather than the use of people as the 'subjects' of research. Many people define public involvement in research as doing research 'with' the public, rather than 'to', 'about' or 'for' the public.

More information is available from:

This project is the focus of my work as a doctoral student at the University of the West of England.

### **Why have you been chosen?**

You are being invited to take part because you are working with research partners in a research study that I would like to investigate. I would like to find out how you have involved research partners, what difference it makes and what it has been like to work with them.

### **Do you have to take part?**

It is up to you to decide whether or not to take part. I will describe my project and go through the information sheet. If you agree to take part you will be asked to sign a consent form.

You are free to withdraw at any time without giving a reason. If you decide to withdraw for any reason, or something happens and you can no longer take part, I would still like to use any information you have already given me for my project. However, you may not agree with this. If you wish I will not use any individual information that you have provided before you withdraw. Your decision about this will be recorded on the consent form.

### **What will you have to do if you take part?**

If you agree to take part in my project I will ask you to give me information in a number of ways over several months (up to a maximum of eighteen months). My aim is to get an in-depth understanding of the research study and of the public involvement taking place; this includes getting to know the people who are involved. In order to do this I would like to do a number of different things. My project takes an ethnographic approach and includes observation, interviews, asking you to take photographs (if you are interested) and collecting documents.

### **Being observed**

If you agree to be observed in the ways described below you are not writing a 'blank cheque' regarding access. My observation of any situation is open to negotiation at all times.

1. I would like to observe you working on the research study with research partners informally and to shadow you when you are working on the study. This means I would take part in informal activities with you and research partners, or spend some time with you specifically while you are working on the study. We would have informal conversations while I am with you, but I would aim not to be too intrusive or to interrupt what you are doing. While I am with you I would like to take some notes as I go along so that I can remember what happened, and also to make audio recordings of what happens and of our conversations when this is acceptable to you. I would be guided by you, by research partners and anyone else involved as to what is appropriate in any situation and when my presence is too intrusive. If you agree to be observed we will discuss and agree what is appropriate in each situation, you will not have given me unlimited access to your activities. I would like to make observations so I can get a good sense of what you and the research partners are doing, so that I can understand more about the research study more generally and the part of the National Health Service or university in which it is taking place.
2. I would like to make some observations without taking part. I would like to come along to research meetings which include research partners, to other research study meetings and to observe other more 'formal' research activities both including and not including research partners. If you agree to be observed we will discuss and agree which activities can be observed in this way, you will not have given me unlimited

access. With permission I will record what happens on a digital recorder and I will also make notes about what I see and hear. After the meeting or activity I will type up the recording of what happened and my handwritten notes.

Observation might include data collection from your own research participants. Whether or not this is possible will be agreed with the chief investigator in advance, and additional informed consent would be requested. I would be interested in observing data collection if research partners have made suggestions about this process which you are implementing, and if research partners are involved in data collection. Observing you collect data from your research participants may also be an important way to understand the work of your research study. Such observation would be conducted with particular sensitivity and only with express agreement of all concerned.

If any observations include people who do not know who I am or what I am doing I will be introduced and explain what I am doing. If anyone is identified while an observation is being conducted who might contribute to my project verbal information about my project will be provided, with a written information sheet and I will answer any questions they may have. I will seek written consent from them to collect data for my project.

### **Being interviewed**

3. I would like to interview professional researchers working on the study. In some studies this will include all researchers but in a large study it would include some researchers. The exact number and who is most appropriate will be discussed and agreed.

If you are one of the researchers being interviewed I would like to meet with you at least twice over the time I am collecting information about the research study. The interviews will only include you and me. An interview is likely to take up to 45 minutes. The interviews will take place somewhere convenient for you at a time you choose. This could be in your office or at some other quiet, convenient and private location agreed between us in advance. You will be free to end or leave the interview whenever you wish. I would like to digitally record the interview and I will ask your permission to do this at the start. After the interview I will type up the recording of what was said.

### **Taking some photographs**

4. If you are interested I would like you to take a few photographs (not more than 5) on a disposable camera which I will give you. The aim is for you to take pictures that in some way represent your experience of public involvement in the study, what working on the study is like more generally and/or your feelings about public involvement. After you have taken the photos I will ask you to return the camera to me. I will develop the photos and send them to you. We will arrange a time to meet at your convenience so that we can look at the photos together and you can tell me a bit about why you took them and what they mean to you. You can keep a copy of the photos if you wish. With your permission I would like to digitally record this discussion. After the discussion I will type up the recording of what was said.

## Collecting documents about the study

5. I would like to collect copies of study documents for my project to see whether and how public involvement is described. This might include what was written in the application for funding, the study protocol and any other documents that might be relevant including published articles if they are available. I would also like to collect documents which provide contextual information about your research study and the institution/s in which it is taking place. I will ask you to provide me with digital or paper copies.

## What do you have to do?

When I come to **observe** you informally or shadow you I would like you to let me accompany you and to talk to me about what you are doing when this is appropriate. I would try not to disrupt your work and I will stop observing you at any time you find me too intrusive. When I observe a meeting or other more 'formal' research activities that you take part in I will not take part and I hope you will carry on as you would if I were not there as much as possible.

In the **interviews** I will ask you about your experience of public involvement in research. This might include how you decided to involve research partners, what tasks you have asked people to contribute to, and how involvement has worked out in practice. I would also like to ask you what difference you feel involvement has made to your study. You will have a chance to tell me about anything you think is relevant. You are free to respond to my questions in any way you like.

It is up to you what **photographs** you take with the disposable camera I give you. The aim is for you to take photos that in some way represent your experience of public involvement in the study, of working on the study more generally and/or how you feel about public involvement. After you take the photos I will ask you to return the camera to me. We will agree to meet at your convenience and look at the photos together so that you can tell me a bit about why you took them. You can keep a copy of the photos if you wish.

I would like to take notes when I observe you informally and digitally record what happens when this feels OK. I would like to take notes and digitally record observations of meetings and other more 'formal' research activities. I would like to digitally record the interviews and discussion about the photos. All recording will take place with your permission. Taking notes and recording will be done so that I have an accurate record of what happened.

When I collect **documents** from you I will need either a paper copy of the document or, ideally, a digital copy which I would put on a computer memory stick. I will transfer any digital documents onto a password protected computer as soon as possible. Documents will not be kept on a memory stick after transfer.

When I have typed up transcripts of observations, interviews or discussions about photographs that you have contributed to you will have the opportunity to check my transcripts for accuracy and make any further comments on them if you wish.

## What are the possible disadvantages or risks of taking part?

I do not think there will be any risks in taking part in my project; however, it is possible that you might find talking about your experience of public involvement a bit distressing if it has been a difficult experience for you. If this happens our contact can stop if you wish or you can take a break. If you would prefer to stop the interview I will check whether or not you are willing for me to contact you to see how you feel about meeting again to complete the

interview. I will check whether you have any support needs and, if so, how they might be met. I will provide some written information about possible sources of support.

It is possible that being observed might feel intrusive, awkward or uncomfortable. I will be as sensitive as possible to you and to the work of the research study and will stop observing if you feel it is too intrusive or inappropriate. I hope that as you get to know me and get used to my presence you will feel more at ease.

### **What are the possible benefits of taking part?**

You may find that talking about what you are doing, your experiences and views and sharing your photos is interesting and gives you an opportunity to reflect on what public involvement has been like for you. I hope you will enjoy taking part.

### **What happens when the research study stops?**

If the project stops early for any reason I will explain this to you.

### **What if something goes wrong?**

If you have any complaints about me or are unhappy about any aspect of taking part in my project you can contact me or my supervisor, Dr David Evans at the University of the West of England (UWE). His contact details are at the end of this information sheet. All complaints will be handled sensitively and be looked into by UWE, in line with UWE's complaints procedure. You will be kept informed during this process.

In addition, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated while you take part in my project, the normal National Health Service complaints mechanisms will also be available to you.

### **Will taking part in this project be kept confidential?**

Yes, all the information I collect from you will be treated in strict confidence and anything I hear or see while I am observing you will be treated in strict confidence and will not be discussed with anyone outside my project.

All information collected will be anonymised and will be stored securely. The information will only be seen by me and my supervisors/advisors. Research partner names and contact details will be kept separately in a locked filing cabinet. Identifiable personal information will be kept up to one year after the project ends and will be disposed of securely. No details that would identify you, the research partners or the study will be used when I write up the project. I may change names and some identifying details in my thesis. I may include quotes from what you say, but I will not identify who said them. I may include your photos in publications; any identifying details will be obscured.

When I write about public involvement in a research study linking together information provided by different people you will be able to read and amend what I say before it is finalised. This is to make sure you feel comfortable about what I write. I will do this because it may be possible for people working together to identify each other even if information is anonymised.

I will use the information to write my PhD thesis, when I write articles for publication in journals and when I give presentations about my project. All information will be stored securely on University computers, it will be kept for six years and then disposed of securely.

### **What will happen to the findings from the research study?**

Towards the end of my project I will write up my findings in a short report which I will send to you and offer to come and make a presentation anyone who has taken part from your research study. I will use the information I collect to write my PhD thesis, in articles for publication in academic journals and when I give presentations about what I have found out. You will not be identified in any report or publication unless you give me your consent.

### **Who is organising and funding the research?**

I am organising the project as a doctoral student in the Faculty of Health and Life Sciences at the University of the West of England (UWE) Bristol. I am funded by UWE in my studies. I have a supervision team of three people; Dr David Evans is my Director of Studies.

### **Who has reviewed the study?**

This project has been reviewed by an NHS Research Ethics Committee. The research has also been reviewed by my supervision team, by the Faculty Research Committee and the Faculty Ethics Committee at UWE.

### **Contact information**

Further information is available from:

Rosie Davies, Blue Lodge, Glenside Campus, University of the West of England, Blackberry Hill, Bristol BS16 1DD. Tel: 0117 328 8796 (shared line).

Email: [Rosemary3.Davies@uwe.ac.uk](mailto:Rosemary3.Davies@uwe.ac.uk)

Professor David Evans, Director of Studies, Room 2G07, Glenside Campus, University of the West of England, Blackberry Hill, Bristol BS16 1DD. Tel: 0117 328 8750.

Email: [David9.Evans@uwe.ac.uk](mailto:David9.Evans@uwe.ac.uk)

You can keep this information sheet about the project. If you decide to take part in my project or if you want any further information please let me know and I will get in contact with you. If you agree to take part you will be asked to sign that you have read and understood this information and that you are happy to take part in my project. You will be given a copy of the signed consent form to keep.

**Thank you for taking the time to read this information**

**Rosie Davies**

## Appendix 13: Consent form



University of the  
West of England

Rosie Davies, Doctoral Student  
Faculty of Health and Life Sciences  
University of the West of England  
Blue Lodge, Glenside Campus  
Blackberry Hill  
Bristol BS16 1DD

### CONSENT FORM

**What is going on in public involvement in health research? An ethnographic exploration of the aims, processes and outcomes of public involvement in three health research studies.**

Please initial boxes below

1. I confirm that I have read and understood the information sheet for this project, version 3.0, 20 December 2011. I have had the opportunity to consider the information and ask questions which have been answered to my satisfaction.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason.
3. I agree to take part in this project in the ways identified below.
4. I agree to being observed, to notes being taken and to being audio recorded.
5. I agree to being interviewed and being audio recorded.
6. I agree to take photos, share them in discussion and for the discussion to be audio recorded. I agree to the use of anonymised photos in publications.
7. I agree to share project documentation and articles.
8. I agree to the use of anonymised quotes in publications.
9. If I withdraw from the project, or can no longer take part for any reason, I agree that information already provided by me can still be used in the project. If I withdraw the decision I take now can be reconsidered.

.....

Name of participant	Date	Signature
.....	.....	.....
Name of researcher	Date	Signature

## Appendix 14: REC favourable opinion 29 September 2011



### National Research Ethics Service NRES Committee South West - Exeter

South West REC Centre  
Level 3  
Block D  
Lewins Mead  
Whitchurch  
Bristol  
BS1 2NT

Telephone: 0117 342 1332  
Facsimile: 0117 342 0443  
e-mail: [Local-IT.SouthWest2@nres.nhs](mailto:Local-IT.SouthWest2@nres.nhs)

29 September 2011

Ms Rosemary Davies  
University of the West of England  
Faculty of Health and Life Sciences  
Glenside Campus  
Blackberry Hill  
Bristol  
BS16 1DD

Dear Ms Davies

**Study title:** What is going on in public involvement in health research? An ethnographic project.  
**REC reference:** 11/SW/0165

Thank you for your letter of 26 September 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

#### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

#### Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

This Research Ethics Committee is an advisory committee to the South West Strategic Health Authority. The National Research Ethics Service (NRES) incorporates the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England.



Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

#### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering Letter		17 June 2011
Covering Letter		09 August 2011
Covering Letter		26 September 2011
Evidence of insurance or indemnity	UMAL Letters 1 & 2	16 July 2011
Interview Schedules/Topic Guides	1.0	26 July 2011
Investigator CV		08 June 2011
Letter from Sponsor		15 June 2011
Other: CV - Dr David Evans		13 June 2011
Other: CV - Professor Jane Coad		17 June 2011
Other: CV - Dr Nick de Viggiani		13 June 2011
Other: Sheet Providing Sources of Support	1.0	23 September 2011
Participant Consent Form: Consent Form	2.0	25 July 2011
Participant Consent Form: Consent Form Group 2	2.0	25 July 2011
Participant Information Sheet: Information Sheet for Members of the public	2.0	25 July 2011
Participant Information Sheet: Information Sheet for Researchers and Research Managers	2.0	25 July 2011
Participant Information Sheet: Information Sheet - Group 2	2.0	25 July 2011
Protocol	3	23 September 2011
REC application	3.1	17 June 2011
Referees or other scientific critique report	Research Degree Registration	24 January 2011
Response to Request for Further Information		09 August 2011
Response to Request for Further Information		26 September 2011

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

## **After ethical review**

### Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

### Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

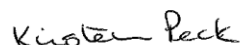
Further information is available at National Research Ethics Service website > After Review

**11/SW/0165**

**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely



pp **Dr Denise Sheehan**  
**Chair**  
**NRES Committee South West - Exeter**

*Enclosures:* "After ethical review – guidance for researchers" [SL-AR2]

*Copy to:* Robin Means (Robin.Means@uwe.ac.uk)

## Appendix 15: NHS Permission for Research 2 December 2011

University Hospitals Bristol 

NHS Foundation Trust

Research & Development Department

Level 3, Education Centre

Upper Maudlin Street

Bristol BS2 8AE

Tel: (0117) 342 0233 Fax: (0117) 342 0239

Ms Rosemary Davies  
University of the West of England  
Faculty of Health and Life Sciences  
Glenside Campus, Blackberry Hill  
Bristol

BS16 1DD

02 December 2011

**NHS Permission for Research has been granted for the study detailed below at University Hospitals NHS Foundation Trust. Permission is subject to any conditions and is effective from 02/12/2011 until 31/08/2013**

Dear Ms Davies

**ID: ME/2011/3884 What is going on in public involvement in health research? An ethnographic project**

NHS permission for the above research has been granted on the basis described in the application form, protocol and current supporting documentation for which a favourable opinion has been given by an authorised REC.

Permission is granted on the understanding that the study is conducted in accordance with the Research Governance Framework, Good Clinical Practice, and NHS Trust policies and procedures available at <http://www.uhbristol.nhs.uk/research/information-for-researchers/post-approval.html>.

NHS indemnity is provided as detailed in the application for the period of permission given above. Requests for changes to the period of permission (eg an extension of the study) must be made to the Research Management Office before permission ceases with an explanation as to why the change is being sought.

#### CONDITIONS WHICH MUST BE MET PRIOR TO RECRUITMENT COMMENCING

- A site file is set-up and delegation log established
- Relevant Letters of Access obtained.

#### CHANGES TO THE STUDY

The research sponsor or the Chief Investigator, or the local Principal Investigator at a research site, may take appropriate urgent safety measures in order to protect research participants against any immediate hazard to their health or safety. The Research Management Office should be notified that such measures have been taken. The Research Management Office should be notified within the same time frame as notification to the REC and any other regulatory bodies. The notification should also include the reasons why the measures were taken and any plan for further action.

All amendments (including changes to the local research team) need to be submitted in accordance with guidance in IRAS. Information concerning a change to status of project

should also be notified.

Please note that the University Hospitals Bristol NHS Foundation Trust (UH Bristol) is required to monitor research to ensure compliance with the Research Governance Framework and other legal and regulatory requirements. Monitoring will be undertaken in accordance with a study specific monitoring plan and can take the form of visits to site, self completion of validation forms and follow-up telephone calls. Investigators who fail to provide timely information on projects may compromise their ability to obtain Trust approval for future work.

Congratulations on initiating this research study. We wish you every success. We are keen to support good research at UH Bristol and are pleased that you have decided to conduct your study here.

Yours sincerely



Mary Perkins  
Deputy Director of Research and Innovation

**References**

<b>CSP_Ref:</b>	
<b>REC Reference:</b>	11/SW/0165
<b>Sponsor:</b>	University of the West of England, Bristol
<b>Chief Investigator:</b>	Davies, Ms Rosemary
<b>Lead Centre:</b>	University Hospitals Bristol

## Appendix 16: UOB study registration 1635 1 December 2011

**From:** Anna Brooke, Research and Enterprise Development  
**Sent:** 01 December 2011 15:52  
**To:** Rosemary Davies  
**Cc:** [REDACTED]; [insurance-enquiries@bristol.ac.uk](mailto:insurance-enquiries@bristol.ac.uk); David Evans  
**Subject:** Study registration 1635

Dear Rosie

Thank you for the additional information regarding your study. Please find below and updated study registration.

Study title: What is going on in public involvement in research? An ethnographic exploration of the aims processes and outcomes of public involvement in three health research studies (our ref 1635) The study will involve UoB Sponsored studies 1378: [REDACTED]: [REDACTED] and 1590: The [REDACTED] study

CI: Rosie Davies (PhD)

Collaborators: [REDACTED]

Sponsor: UWE, 15.6.11, ref RM/lt

Peer review: Dr David Evans, Professor in Health Services Research (Public Involvement)

Ethics: Exeter, 11/SW/0165, 29.9.11

Insurance: n/a - observation and interviewing of healthy volunteers

Participants: Observation of the PPI Panel and interviews with members of the Panel and the research team.

Should you decide you would like to contact study participants then please contact us again for further advice on how to proceed.

Study site: UoB and partner agencies, in the company of a member of UoB research team

Trial duration: December 2011 to August 2013

Please do not hesitate to contact us if you would like further information.

Best wishes

Anna

-----  
Anna Brooke (Weds, Thurs and Fri)  
Research Governance Officer  
University of Bristol  
Research & Enterprise Development  
Senate House, Tyndall Avenue, Bristol BS8 1TH  
Tel: +44 (0) 117 331 7709 (direct)  
Fax: +44 (0) 117 929 8383

For General Enquiries: [research-governance@bristol.ac.uk](mailto:research-governance@bristol.ac.uk) [www.bristol.ac.uk/red](http://www.bristol.ac.uk/red)

Click below to view the RED Highlight Report 2009-10

<https://www.bris.ac.uk/red/about/highlight.pdf>

Find out more about traveling to the University of Bristol in an environmentally friendly way with our online information on bus and train services, the free university shuttle, and cycle routes:

<http://www.bristol.ac.uk/university/maps/>.

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## Appendix 17: UOB Updated study registration 1635 4 September 2012

**From:** Anna Brooke, Research and Enterprise Development  
**Sent:** 04 September 2012 15.58  
**To:** Rosemary Davies  
**Subject:** Updated Study registration 1635

Dear Rosie

Thank you for the additional information regarding your study. Please find below an updated study registration.

Study title: What is going on in public involvement in research? An ethnographic exploration of the aims processes and outcomes of public involvement in three health research studies (our ref 1635)

The study will involve UoB Sponsored studies 1378: [REDACTED] and 1590: The [REDACTED] study and the 3rd study will work with [REDACTED], School of [REDACTED] Sciences, UoB.

CI: Rosie Davies (PhD student at UWE)

Collaborators: [REDACTED]

Sponsor: UWE, 15.6.11, ref RM/lt

Peer review: Dr David Evans, Professor in Health Services Research (Public Involvement)

Ethics: Exeter, 11/SW/0165, 29.9.11

Insurance: n/a - observation and interviewing of healthy volunteers

Participants: Observation of the PPI Panel and interviews with members of the Panel and the research team.

Should you decide you would like to contact study participants then please contact us again for further advice on how to proceed.

Study sites: UoB and partner agencies, in the company of a member of UoB research team, UHBristol - emailed approval from Emma Stoica 24.8.12

Trial duration: December 2011 to August 2013

Please do not hesitate to contact us if you would like further information.

Best wishes

Anna

-----

Anna Brooke  
Research Governance Officer  
University of Bristol  
Research & Enterprise Development  
Senate House, Tyndall Avenue, Bristol BS8 1TH

Tel: +44 (0) 117 331 7709 (direct)

Fax: +44 (0) 117 929 8383

For General Enquiries: [research-governance@bristol.ac.uk](mailto:research-governance@bristol.ac.uk) [www.bristol.ac.uk/red](http://www.bristol.ac.uk/red)

Please note that a new RED website has been launched.

Information has been added to the research governance webpages and you might find it a useful resource. The new link is:

<http://www.bristol.ac.uk/red/research-governance/>

Find out more about traveling to the University of Bristol in an environmentally friendly way with our online information on bus and train services, the free university shuttle, and cycle routes:

<http://www.bristol.ac.uk/university/maps/>.

This email and any attachment is for authorised use by the intended recipient(s) only. It may contain proprietary material, confidential information and/or be subject to legal privilege. It should not be copied, disclosed to, retained or used by, any other party. If you are not an intended recipient then please promptly delete this email and any attachment and all copies and inform the sender. Thank you.



## Appendix 18: UWE Faculty Research Ethics Permission 14 February 12



Faculty of Health & Life  
Sciences  
Glenside Campus  
Blackberry Hill  
Stapleton  
Bristol BS16 1DD

Tel: 0117 328 1170

Our ref: JK/lt

09 March 2016

Mrs Rosemary Davies

UWE

Glenside Campus

Dear Rosie

**Application number: HLS/12/01/22**

Application title: What is going on in public involvement in health research? An ethnographic project

NHS Application Number: 11/SW/0165

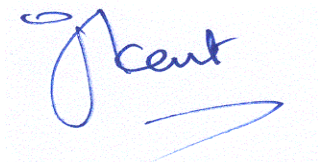
Your NHS Ethics application and approval conditions have been considered by the Faculty Research Ethics Committee on behalf of the University. It has been given ethical approval to proceed with the following conditions:

- You comply with the conditions of the NHS Ethics approval.
- You notify the Faculty Research Ethics Committee of any further correspondence with the NHS Ethics Committee.
- You notify the Faculty Research Ethics Committee in advance if you wish to make any significant amendments to the original application.
- Please note that all information sheets and consent forms should be on UWE headed paper.
- If you have to terminate your research earlier than planned, please inform the Faculty Research Ethics Committee within 14 days, indicating the reasons.
- Please notify the Faculty Research Ethics Committee if there are any serious events or developments in the research that have an ethical dimension.
- Please be advised that as principal investigator you are responsible for the secure storage and destruction of data at the end of the specified period a copy of the guidelines are enclosed for your information.

Please note that your study should not commence at any NHS site until you have obtained final management approval from the R&D department for the relevant NHS care organisation. A copy of the approval letter(s) must be forwarded to Leigh Taylor in line with Research Governance requirements.

We wish you well with your research.

Yours sincerely

A handwritten signature in blue ink, appearing to read 'J Kent', with a long horizontal flourish extending to the right.

Prof Julie Kent

Chair

Faculty Research Ethics Committee

**Appendix 19: Letter of Access for University Hospitals Bristol NHS  
Foundation Trust 18 January 12**

University Hospitals Bristol   
NHS Foundation Trust

**PRIVATE AND CONFIDENTIAL**

Ms Rosemary Davies  
20 Melbourne Road  
Bishopston  
Bristol  
BS7 8LB

**[Jobs@UHBristol](mailto:jobs@uhbristol.nhs.uk)**  
Level 3, Education Centre  
Upper Maudlin Street  
BRISTOL  
BS2 8AE  
Tel: 0117 342 5000  
- option 1  
Email: [jobs@uhbristol.nhs.uk](mailto:jobs@uhbristol.nhs.uk)

**18 January 2012**

Dear Rosemary

**Letter of access for UH Bristol R&D Number: ME/2011/3884 Public Involvement in  
Health Research**

This letter confirms your right of access to conduct research through UH Bristol or the purpose and on the terms and conditions set out below. This right of access commences on **18 January 2012** and ends on **1 January 2015** unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation UH Bristol. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

The information supplied about your role in research at UH Bristol has been reviewed and you do not require an honorary research contract with this NHS organisation. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.

You are considered to be a legal visitor to UH Bristol premises. You are not entitled to any form of payment or access to other benefits provided by this NHS organisation to

employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through UH Bristol you will remain accountable to your employer the **University of the West of England** but you are required to follow the reasonable instructions of [REDACTED] in this NHS organisation or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with UH Bristol policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with UH Bristol in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on UH Bristol premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf>) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

UH Bristol will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely

**Judith Reed,**  
**Operations Manager - Recruitment**

CC: R&D Office, UH Bristol



Professor Robin Means, UWE

## Appendix 20: Sources of support

### Sources of support

#### **General sources of support:**

**Citizens Advice Bureau** provides information about NHS patients' rights. This includes services from family doctors (GP's). Information is available from the following website page:

[http://www.adviceguide.org.uk/index/your\\_family/health\\_index\\_ew/nhs\\_patients\\_rights.htm](http://www.adviceguide.org.uk/index/your_family/health_index_ew/nhs_patients_rights.htm)

**Patient.co.uk** is a website that gives comprehensive health information and has details of 1800+ UK patient support organisations and self help groups.

Website address: <http://www.patient.co.uk/>

**Samaritans** offer support at any time of the day for anyone in distress 24 hours a day.

Phone number: 08457 90 90 90

Email: [jo@samaritans.org](mailto:jo@samaritans.org)

Website address: <http://www.samaritans.org/>

#### **Support related to rheumatoid arthritis:**

##### **Researchers in the Rheumatology Unit at University Hospitals Bristol NHS Foundation Trust.**

If you have any concerns or worries related to working as a patient research partner on a research study in the Rheumatology Unit in Bristol please contact the Principal Investigator of the study you work on or the Patient Research Partner Coordinator/Supporter. If you have any worries about your rheumatoid arthritis you could contact a specialist nurse at the Rheumatology Unit.

**National Rheumatoid Arthritis Society (NRAS).** NRAS has a Helpline open Monday-Friday between 9.30 am and 4.30 pm. NRAS has trained volunteers with RA who offer general support. Call the Helpline to arrange for a volunteer to call.

Freephone number: 0800 298 7650

Email: [helpline@nras.co.uk](mailto:helpline@nras.co.uk)

Website address: <http://www.nras.org.uk/>

**Arthritis Care.** Arthritis Care has a Helpline open from 10.00 am to 4.00 pm weekdays. The Helpline can also be contacted by email.

Phone number: 0808 800 4050 (Free from landlines and most mobile providers.)

Email: [Helplines@arthritiscare.org.uk](mailto:Helplines@arthritiscare.org.uk) Website address:

<http://www.arthritiscare.org.uk/Home>

**Support related to domestic violence:**

Information about domestic violence including sources of support is provided by the following website

[http://www.direct.gov.uk/en/crimejusticeandthelaw/victimsofcrime/dg\\_4003136](http://www.direct.gov.uk/en/crimejusticeandthelaw/victimsofcrime/dg_4003136)

**24 hour National Domestic Violence Freephone Helpline 0808 2000 247.**

The Helpline can give support, help and information over the telephone, wherever the caller might be in the country. The Helpline is staffed 24 hours a day by fully trained female helpline support workers and volunteers. All calls are completely confidential.

Website address: <http://www.nationaldomesticviolencehelpline.org.uk/>

**Support related to cancer:**

**Macmillan Cancer Support** provide information, advice and information about a variety of sources of support. They have a team of experts who can answer any questions you have, offer support, or simply listen if you need a chat.

Call free on 0808 808 00 00                      Monday-Friday 9.00 am – 8.00 pm

Website address: <http://www.macmillan.org.uk/Home.aspx>

**Cancer Information and Support Centre.** The Cancer Information and Support Centre is based at University Hospitals Bristol NHS Foundation Trust is a drop in centre open from Monday-Thursday 9am-5pm and Friday 9am – 4.30 pm. Address: Bristol Haematology and Oncology Centre, Horfield Road, Bristol BS2 8ED

Telephone helpline available on 0117 342 3369.

Website address: <http://www.uhbristol.nhs.uk/patients-and-visitors/your-hospitals/bhoc/information-and-support/information-and-support-centre/>

**Penny Brohn Cancer Care** offers specialist support including complementary therapies, advice and counselling for people living with cancer and their supporters. All services are free.

Helpline number: 0845 123 23 10                      Monday to Friday 9 am – 5 pm

Email: [helpline@pennybrohn.org](mailto:helpline@pennybrohn.org)

Website address: <http://www.pennybrohncancercare.org/page1.asp>

## Appendix 21: Background information form

Participant number: .....

### *Background Information*

**CONFIDENTIAL**

***All information provided will be treated as strictly confidential.***

***Please tick one box for each question except question 3.***

1. Are you  female  
 male
  
2. What is your age?  under 25 years  
 25-45 years  
 46-64 years  
 65 years and over
  
3. Are you (please tick **all** boxes that apply to you)  
 in full-time paid work  
 in part-time paid work  
 in unpaid or voluntary work  
 not working  
 retired  
 a student  
 looking after children, family members or friends with long-term physical or mental ill-health/disability or with problems related to old age
  
4. Are you  an academic or clinical researcher  
If so are you a  Chief investigator (CI) or Principal investigator (PI)  
Please write in job title: .....  
 a member of the public (for example, a research partner, patient, service user, carer, parent)  
 a research manager  
 other Please write in: .....
  
5. What qualifications do you have?  
 No qualifications  
 CSE/'O' Level/GCSE/NVQ level 1 or 2  
 'A' Level/'S' Level/Higher School Certificate/BTEC National/ONC/OND/NVQ Level 3  
 First degree (for example, BA, BSc) HND or professional qualification (for example RGN)  
 Masters degree and above (for example, MA, MSc, PhD, PGCE)



6. What is your ethnic group?
- A. White
- English / Welsh / Scottish / Northern Irish / British
  - Irish
  - Gypsy or Irish Traveller
  - Any other White background, please write in: .....
- B. Mixed / multiple ethnic groups
- White and Black Caribbean
  - White and Black African
  - White and Asian
  - Any other Mixed/multiple ethnic background, please write in: .....
- C. Asian / Asian British
- Indian
  - Pakistani
  - Bangladeshi
  - Chinese
  - Any other Asian background, please write in .....
- D. Black / African / Caribbean / Black British
- African
  - Caribbean
  - Any other Black / African / Caribbean background, please write in .....
- E. Other ethnic group
- Arab
  - Any other ethnic group, please write in .....
7. What is your religion?
- No religion
  - Christian (including Church of England, Catholic, Protestant and all other Christian denominations)
  - Buddhist
  - Hindu
  - Jewish
  - Muslim
  - Sikh
  - Any other religion, please write in .....
8. What is your sexual orientation?
- Heterosexual
  - Lesbian
  - Gay
  - Bisexual
  - Any other sexual orientation, please write in .....
9. Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months?
- Yes, limited a lot
  - Yes, limited a little
  - No

Thank you very much.

## Appendix 22: Demographic characteristics of participants

		Research Partner (n=18)	Researcher (n=20)	Agency (n=8)	Total (n=46)
<b>Sex</b>	Male	1	2	0	3
	Female	17	18	8	43
	Unknown	0	0	0	0
<b>Age Group</b>	Under 25 years	2	0	0	2
	25-45 years	6	7	2	15
	46-64 years	4	9	1	14
	65 years and over	2	0	0	2
	Unknown	4	4	5	13
<b>Occupation</b>	Full time paid	0	10	2	12
	Part time paid	3	5	0	8
	Unpaid or voluntary	1	0	0	1
	Retired	3	0	0	3
	Not working	5	0	0	5
	Looking after children/elderly relatives	2	0	0	2
	Unknown	4	5	6	15
<b>Qualifications</b>	None	1	0	1	2
	O Level	5	0	0	5
	A Level	4	0	0	4
	First degree	4	0	2	6
	Masters and above	0	16	0	16
	Unknown	4	4	5	13
<b>Ethnic group</b>	White	11	14	2	27
	Asian/Asian British	0	1	0	1
	Mixed/multiple	1	0	1	2
	Other	2	0	0	2
	Unknown	4	5	5	14
<b>Religion</b>	No religion	6	5	2	13
	Christian	5	6	0	11
	Muslim	1	1	0	2
	Other	1	0	1	2
	Unknown	5	8	5	18
<b>Sexual orientation</b>	Heterosexual	14	12	2	28
	Lesbian	0	2	1	3
	Unknown	4	6	5	15
<b>Day to day activities limited</b>	No	6	14	3	23
	Yes, limited a little	5	0	0	5
	Yes, limited a lot	3	0	0	3
	Unknown	4	6	5	15

## **Appendix 23: Support and Safety Agreement**

### **Support and Safety Agreement**

**Linked to Safety Guidance Note April 06 UWE**

#### **Fieldwork sites:**

The majority of fieldwork – observations and interviews - in my PhD project will take place in institutional settings where research meetings are conducted. This will include academic and clinical environments as well as meetings conducted in third party organisations. Fieldwork is unlikely to be conducted in hospital wards.

Most interviews will take place in institutional settings but some may take place at the homes of research partners.

#### **Risk:**

It is unlikely that data collection will precipitate distress or anger. My PhD project is focused on experiences of involvement in research not on experiences of receiving health services or on difficult personal or social issues. Nonetheless, it is possible that participants may share personal experiences of illness and health care if such experiences prompted involvement in research. However, disclosure will be the choice of the participant, for example, when providing background information; it will not be initiated by specific research questions.

It is possible that reflecting on involvement in research may be distressing if such experiences have been difficult. There is a procedure for responding to distress within the project protocol.

#### **Interview arrangements:**

Interviews will not be conducted in participant's homes unless I have met them in an institutional setting in advance and feel comfortable to meet at their home. I will ensure that my mobile phone is charged and switched on while conducting interviews at participant's homes.

If an interview takes place in someone's home I will inform David Evans where and when the interview will take place, including the address, telephone number and name of the participant, and when the interview should be finished. I will arrange to call DE to report that the interview is completed. If DE is not available I will ask either Jane Coad or Nick de Viggiani to take on this role. The 'acting' supervisor will be notified if changes are made to interview plans, or interviews are cancelled or postponed.

If no call is made by me after an interview, after 30 minutes DE will call me on my mobile – which will be left on. If there is no reply he will call the participant to ask about my whereabouts. If I cannot be found DE will call the police.

#### **Support**

It is possible that the collection of data may cause me some distress. This could be the result of the focus of research activity, for example, aspects of domestic violence, or the result of difficult events or relationships with researchers or research partners in the participating studies.

If I am distressed after collecting data I will contact DE to discuss the situation and my support needs. If I anticipate that collecting data will be difficult or distressing I will discuss identified issues with my supervisors in advance.

## Appendix 24: Nvivo screen shots of data extract, and examples of the structure of codes and themes in development

The screenshot displays the Nvivo software interface. The top menu bar includes File, Home, Create, External Data, Analyze, Query, Explore, Layout, and View. The ribbon contains various tool groups such as Navigation View, Find, Quick Coding, Workspace, Window, List View, Coding, Highlight, Annotations, See Also Links, Relationships, Links, Node, Node Matrix, Report, Framework Matrix, Classification, Reference, and Visualization.

The main window is divided into two panes. The left pane shows a text extract with the following content:

just done .. they couldn't get somebody to print it for nothing [mm] I mean the hospital printed it for nothing a couple of times .. but now it's short of money [yea] and they said oh well we have got this newsletter but we can't get it printed, well .. we have just printed it for them [mm] right .. ok so it cost us .. I don't know .. sixty quid or something .. right because we just do it through the University set up [mm] yea] so I just used the charity money to pay for it .. [yea .. yea] but .. but therefore, but therefore I have to do it you know and the nurse has to say to me ..you know they can't get their thing printed what can we do, and I have to say right [yea] we will get it printed then, right .. [yea] so you have to be engaged with it without running it .. [mm yea] and so having our nurse educator run the education programme [yea] and having our patient partner supporter running that programme and .. they .. I mean we used to run these little training days for them, now they now tell us what they want us to do on the training days .. [laughs] they come to us and say here is the proposed programme, does that look alright, will you do this bit .. laughs [yea laughs] you know [yea yea] and err and .. it's like with CONFERENCE you know the patient's write the glossary .. the patients at CONFERENCE .. the next CONFERENCE meeting is going to have nine experienced patients and eleven new patients at it, and the nine experienced patients are currently organising a system for supporting the eleven new patients, a buddy system and they are doing .. getting people to write little explanatory notes about the different topics that are going to be at the conference, so that these new people will understand what's going on [mmm] it is brilliant isn't it .. isn't it absolutely brilliant [yea yea] and this is the pay off .. for us investing our time years ago [yea] in it right .. so now it happens, now we have got 26 patients involved in research projects and I can't even, I don't even know them all [yea] but I know it's all going on .. [yea laughs] right .. because we have got the set up, it's built into what we do [yea] and these days whenever we write grant applications .. there is always patient research partners on the grant application, including a bit of money to pay for them to travel to get to the meetings or .. [yea] to pay for .. err um .. I mean and some of them, depending which institution they are running through and who it is that is paying, we actually pay for their time [yea] but we are not at all sure that that is the best way to do things [yea ok I was wondering about that ..yea ] like UNIVERSITY for example, well UNIVERSITY likes to pay for patients time so in projects that run through UNIVERSITY we have got an allowance for patient time [yea] nowhere else [laughs right] we certainly pay expenses, no question about that .. [yea] and if somebody for example had to take a day off work to take part we would pay them a day's wages .. to do that right .. [mm] but the idea that we are actually paying patients stops them from being volunteers and we are .. we are in two minds about this .. I am biased towards not paying .. [mm] like we don't pay for blood donors, right .. [mm] err I think R4's a bit biased towards paying .. but she is employed by an institution that says that that's the policy .. [laughs] laughs right [right yea] but I think that if you talk to her I think that you will find that she is not like sure .. absolutely sure that that's the best thing to do right [yea .. mm] umm .. my own view is that the patients come as volunteers [mm] and .. and I see that as volunteers ... but you know the feedback that we have had from patients .. who have been involved, the positive effect it has had on their lives .. it has been astonishing .. it has been a really really gratifying unexpected outcome of involving patients like this .. [mm]

The right pane shows a hierarchical code structure with the following levels:

- History of involvement
  - Field of research
  - Development of culture and systems
  - Culture and values of team or dept or institution
  - Implementation of PIR or research or other
    - Training
    - Support systems
- Role PIR support job
  - Resources needed for PIR system
  - Recruitment
  - PIR structures
- Confidentiality agreement, glossary, and other documents
- Relationships between partners and researchers
- Leadership
- Leader needs to actively support and find resources
- Takes time and effort
- Shift from clinician role to colleague
- Researchers who are not clinicians at disadvantage for PIR
- Researchers need to be in charge and use their expertise
- PIR ISSUES FOR PARTNERS
- Strategic impact e.g. publications
- On researchers
- On research interests
- On research

At the bottom of the right pane, there are three additional codes: "PIR in grant applications", "On partners", and "Leaders have different views".

The bottom status bar shows: In Nodes, Code At, Nodes: 116, References: 479, Read-Only, Line: 508, Column: 87, 100% zoom, and system time 13:21 07/08/2015.

PhD project.nvp - NVivo

File Home Create External Data Analyze Query Explore Layout View

Navigation View Find Quick Coding Detail View Close All Close Dock All Bookmarks Layout Window

Annotations See Also Links Relationships Annotations See Also Links Relationships Node Node Matrix Report Framework Matrix Classification Previous Next Color Scheme Visualization

Nodes

- Nodes
  - About people
  - Descriptions, links, reflectio
  - Documents for classificatio
  - People
  - Quotes
  - Structuring codes
  - Themes
  - Themes deductive
  - Relationships
  - Node Matrices

Sources

Nodes

Classifications

Collections

Queries

Reports

Models

Folders

RD 339 Items

Look for: Search In Themes Find Now Clear Advanced Find

Themes

Name	Sources	References	Created On	Created By	Modified On	Modified By
1 DOINGS - TASKS AND ROLES	60	457	30/04/2013 14:20	RD	08/04/2015 09:53	RD
2 OUTCOMES & IMPACTS	43	270	30/04/2013 14:21	RD	08/04/2015 09:55	RD
Difficult to identify	7	10	30/04/2013 15:18	RD	07/08/2015 13:02	RD
Limitations to impact	4	6	30/04/2013 15:18	RD	02/05/2013 11:38	RD
On ethics	4	4	30/04/2013 15:18	RD	07/08/2015 13:02	RD
On partners	27	72	30/04/2013 15:18	RD	07/08/2015 13:02	RD
On research	28	54	30/04/2013 15:18	RD	07/08/2015 13:02	RD
On research interests	6	11	30/04/2013 15:18	RD	07/08/2015 13:02	RD
On researchers	21	38	30/04/2013 15:18	RD	07/08/2015 13:02	RD
On team	4	9	30/04/2013 15:18	RD	07/08/2015 12:54	RD
On third sector organisation	8	9	30/04/2013 15:18	RD	12/06/2013 15:13	RD
PI and PIR holistic effects on research, patient care etc	11	18	30/04/2013 15:18	RD	07/08/2015 13:02	RD
PIR not based on evidence so not necessarily about impact	1	3	30/04/2013 15:18	RD	29/01/2013 15:20	RD
Stories of significance	10	15	30/04/2013 15:18	RD	07/08/2015 13:02	RD
Strategic impact e.g. publications	12	21	30/04/2013 15:18	RD	07/08/2015 12:54	RD
3 PEOPLE AND PROCESS	70	1770	30/04/2013 14:21	RD	08/04/2015 10:03	RD
4 STRUCTURES, SYSTEMS, RESOURCES, DOCUMENTS	56	542	30/04/2013 14:22	RD	07/08/2015 12:54	RD
Confidentiality agreement, glossary and other documents	27	40	30/04/2013 15:23	RD	07/08/2015 12:54	RD
Confidentiality and ethics	7	9	30/04/2013 15:23	RD	08/04/2015 10:05	RD
Databases of partners and ways of keeping in touch	3	5	30/04/2013 15:23	RD	08/04/2015 10:05	RD
Formal vs informal	27	58	30/04/2013 15:23	RD	15/08/2013 14:11	RD
Jargon	13	20	30/04/2013 15:23	RD	13/06/2013 12:45	RD
Payment	39	84	30/04/2013 15:23	RD	07/08/2015 13:02	RD
PIR structures	33	131	30/04/2013 15:23	RD	07/08/2015 12:54	RD
Recruitment	36	110	30/04/2013 15:23	RD	07/08/2015 12:54	RD
Resources needed for PIR system	23	43	30/04/2013 15:23	RD	07/08/2015 12:54	RD
Rooms and practicalities	17	27	30/04/2013 15:23	RD	13/06/2013 12:38	RD
TERMINOLOGY AROUND PIR	3	3	28/09/2012 10:35	RD	07/08/2015 12:54	RD
5 LEARNING & DEVELOPMENT	45	164	30/04/2013 14:22	RD	08/04/2015 10:05	RD
Developing in the role	7	14	30/04/2013 14:52	RD	20/05/2013 15:39	RD
Training, support and induction	43	148	28/09/2012 10:20	RD	15/09/2013 14:15	RD
Contact between partners	2	2	01/11/2012 10:59	RD	11/01/2013 14:30	RD
Role PIR support job	13	42	28/09/2012 15:26	RD	07/08/2015 12:54	RD
Support systems	15	22	26/09/2012 15:32	RD	07/08/2015 13:02	RD
Training	20	35	26/09/2012 15:30	RD	07/08/2015 12:54	RD
6 CONTEXT FACTORS	59	791	28/09/2012 10:38	RD	08/04/2015 10:06	RD

RD 339 Items

13:34 07/08/2015

The screenshot displays the NVivo software interface for a project named 'PhD project.nvp'. The main window shows a list of themes under the 'Nodes' tab. The 'Themes' table is as follows:

Name	Sources	References	Created On	Created By	Modified On	Modified By
1 DOINGS - TASKS AND ROLES	59	450	30/04/2013 14:20	RD	08/04/2015 09:53	RD
2 OUTCOMES & IMPACTS	42	251	30/04/2013 14:21	RD	08/04/2015 09:55	RD
3 PEOPLE AND PROCESS	69	1731	30/04/2013 14:21	RD	08/04/2015 10:03	RD
4 STRUCTURES, SYSTEMS, RESOURCES, DOCUMENTS	55	529	30/04/2013 14:22	RD	08/04/2015 10:05	RD
5 LEARNING & DEVELOPMENT	44	161	30/04/2013 14:22	RD	08/04/2015 10:05	RD
6 CONTEXT FACTORS	58	754	28/09/2012 10:38	RD	08/04/2015 10:06	RD
7 PIR AIMS AND PURPOSES	1	1	30/04/2013 14:37	RD	07/06/2013 15:03	RD
8 LEGITIMACY AND REPRESENTATION	18	35	30/04/2013 14:38	RD	13/01/2014 10:36	RD
9 VISIBILITY AND EVIDENCE	1	3	30/04/2013 14:38	RD	02/05/2013 12:33	RD
99 POWER	13	28	30/10/2012 11:08	RD	14/01/2014 12:36	RD

The interface includes a top menu bar with options like File, Home, Create, External Data, Analyze, Query, Explore, Layout, and View. A left sidebar shows a tree view of nodes, with 'Nodes' selected. A bottom taskbar shows various application icons and the system clock indicating 10:51 on 07/08/2015.

## Annotations to Appendix 25

Appendix 25 shows three screen shots from Nvivo 9 (QSR International 2010). These screen shots show coding and themes in development.

### First screen shot

Page 346 shows a screen shot of coding. The box on the left of the page shows the anonymised text of the interview. The box on the right shows coding labels and vertical coloured bars identify segments of the transcript that connect to particular codes. For example, coding for *PIR (public involvement in research) in grant applications* is shown as the dark bar nearest to the text; coding for impact *on (research) partners* is shown as the yellow bar at the bottom of the page. A segment at the top of the text was coded both for *leadership* (the green bar) and for *resources needed for PIR (public involvement in research) systems*.

### Second screen shot

Page 347 shows a second screen shot of inductive themes from the *themes* folder. Some of the themes have been expanded to show levels of subordinate themes and codes. For example, under theme *2 OUTCOMES & IMPACTS* there are subordinate themes showing impacts *on (research) partners, on research, and on researchers*. The plus sign next to *on (research) partners* and *on research* show that there are further subordinate codes within these sub-themes.

Under theme *5 LEARNING & DEVELOPMENT* the subordinate theme training support and induction has been expanded to show the next level of subordinate themes. This includes the node *Training* and the screen shot on page 346 shows a short segment coded for this node in yellow.

### Third screen shot

Page 348 shows ten theme headings prior to final refinement. Themes 1 and 7 shown here were combined in the theme *involvement tasks and roles* that appear in section 4.6 on page 92. Themes 2 and 6 appear in the final structure with amended headings. Themes 3, 4 and 5 were combined in the final theme titled *processes, mechanisms and resources*. Theme 8 was amended by the addition of the sub-theme *recruitment* shown on page 347 to form the final theme *who was involved*. There were few data related to theme 9 so this theme did not appear in the final structure. Theme 99 did appear in the final structure.

## **Appendix 25: Reflection on identity, disclosure and position**

My identity included being a mental health service user and experienced research partner. Since my diagnosis with bi-polar disorder I had chosen to routinely disclose my diagnosis and use of mental health services in involvement roles, related to a sense of changed identity. In this project I disclosed my mental health service user status and involvement experience to all participants when I first met them. My involvement experience, including working with some high profile senior researchers in the area and membership of NIHR INVOLVE, was evident in the CV I presented to the senior researchers with whom I negotiated the conduct of my case studies.

Disclosing mental health problems to research partner participants established my identity as someone who had experienced serious health problems with ongoing and stigmatising implications. I hoped that this would help to 'level the playing field' to some extent because I was sharing information as well as seeking it. However, in data collection I was not seeking information about participants' personal experiences of rheumatology or domestic violence, so the terrain of the interviews did not draw directly on this kind of experiential expertise. I disclosed my own experiences of involvement to help to probe responses and check my understanding, and occasionally I shared ideas emerging from data analysis when I felt they were related to participants' contributions to enable critical comment on my ideas (Pawson 1996).

My position included having paid involvement roles and research roles, while also continuing to work as a research partner. This required ongoing consideration of self-disclosure in different contexts where different norms and expectations were in tension with each other. Inhabiting situations with complex role boundaries which drew on different parts of my experience and identity in different ways at different times was familiar to me, and entailed ongoing consideration of others' expectations and norms as well as reflexive self-monitoring; these prior experiences supported my ability to negotiate boundary issues within my project.

My involvement experience situated me as having relevant expertise in relation to the topic of my project and I was a member INVOLVE. I had ongoing working relationships with researchers and research partners from different universities and hospitals in the area. This included working with two of my supervisors, including my director of studies. My position, including prior relevant experience and contacts, supported my ability to negotiate access to start this project. In addition, I had access to my director of studies' network of contacts; his position included being an academic in the field and membership of INVOLVE. Relations with project participants therefore took place within ongoing relationships and work in involvement. Prior relationships with researchers were of direct benefit; a senior researcher recommended me and my project to a colleague and this



facilitated recruitment of the DV case study and both senior researchers in the rheumatology case study were supportive of my project.

My position as a research partner may have positively affected recruitment of research partners, no research partner approached refused to participate in my project. In relation to data collection my experience gave me significant insider knowledge to draw on which helped me to understand and enquire about participants' experiences of involvement. However, my experiential expertise was related to mental health problems, not to rheumatoid arthritis or domestic violence, so there were significant areas of difference from research partner participants. In addition, I had a lot more involvement experience than all the research partner participants in the DV case study. However, in the rheumatology case study most research partner participants also had significant involvement experience so we had more in common. Sharing experiences of involvement in this project did not necessarily produce the kind of connection, curiosity and personal sharing that I had experienced when disclosing my experiences of mental health problems to other service users in mental health research.