



UNIVERSITY OF
LIVERPOOL

A multi-sited ethnography of patient and public involvement in
epilepsy research

Thesis submitted in accordance with the requirements of the University of Liverpool for the
degree of Doctor of Philosophy

By

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Declaration

This thesis is the result of my own work. The material contained in this thesis has not been presented, nor is currently being presented, either in part or wholly for any other degree qualification.

I designed this research in conjunction with my supervisors and was solely responsible for data collection, analysis and write-up.

Abstract

A multi-sited ethnography of patient and public involvement in epilepsy research.

Contemporary health policy and funding bodies are placing increasing emphasis on patient and public involvement (PPI) in healthcare and health research, advocating PPI in all stages of the research process. Currently, however, there is limited empirical evidence critiquing different approaches to PPI or exploring its associated benefits and challenges. Without this information researchers and patient/public representatives cannot make informed decisions about best practice.

The principal aim of this thesis was to generate a detailed understanding of the implementation of PPI in health research. To accomplish this broad aim, I focused on a specific health condition, epilepsy, and the research structures underlying health research in the UK, namely, research networks. I achieved this using a multi-sited, ethnographic approach, incorporating multiple qualitative data collection methods, including 47 interviews, 35 observations, fieldnotes and document analysis.

My in-depth thematic analysis of the data found that PPI is conceptualised in terms of 'meaningful' and 'tokenistic' involvement by those engaged in the process, rather than how it is depicted in the current models of involvement. Having first explored these terms I identified five components that can help to ensure that PPI is meaningful and not tokenistic. Having compared and contrasted multiple approaches to PPI I conclude that there is not one single 'best approach' for implementing PPI. Rather, to achieve high 'quality' PPI there is a need to incorporate seven methodological factors that overarch approaches and ensure that there is an alignment of approach and purpose.

Both the professionals and the patient/ public representatives within my research appeared to be highly aware of the moral and political motivations of PPI, but were primarily motivated by pragmatic or consequentialist reasons. Professionals were motivated almost exclusively by the goal of improving the applicability or relevance of the research. This goal was important for representatives too but they were also motivated by a range of personal reasons, including the wish to feel they were making a difference; the opportunity to learn about epilepsy and epilepsy research; and the opportunity to interact with others. The perceived benefits of PPI were also identified and discussed in depth, and appeared to be largely congruent with those reported in the literature. However, my work has identified some challenges and barriers around PPI that have not previously been explored including: adverse emotional effects; organisational practicalities; concerns about 'representativeness' and 'tokenism'; the 'blurring' of roles and the erosion of patient-clinician boundaries.

I conclude by recommending that there should be an increased focus on appropriate, 'meaningful', involvement rather than endeavouring to implement PPI in all stages of the research process, as currently advocated in policy documents. The insights into the challenges of PPI that my work has provided will allow them to be addressed from the outset, improving the PPI experience and consequently the likelihood of PPI being successfully implemented.

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Just like it ‘takes a village’ to raise a child, I could not have produced this thesis without the help, advice, support and above all patience of many people, only some of whom is it possible to give particular mention to here.

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It must be noted, that despite all of their help, responsibility for all of the weaknesses and shortcomings in this thesis remain my own.

“Where to start is the problem, because nothing begins when it begins and nothing’s over when it’s over, and everything needs a preface, a postscript, a chart of simultaneous events.... Any point of entry is possible and all choices are arbitrary.”

Atwood, M. (1993). *The Robber Bride*. London: Virago

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Abbreviations

CEN	Comparator Epilepsy Network
CCRN	Comprehensive Clinical Research Network
CP	Clinical Practitioner
CS1	Child Site One
CS2	Child Site Two
CSG	Clinical Study Group
DH	Department of Health
EA	Epilepsy Action
EARN	Epilepsy Action Research Network
ILAE	International League Against Epilepsy
IPA	Interpretative Phenomenological Analysis
MG	Management Group
MRC	Medical Research Council
NC	Network Coordinator
ND	Network Director
NHS	National Health Service
NIHR	National institute of Health Research
NL	Network Lead (Patient Public Involvement)
NWHTMR	North West Hub for Trials Methodology Research
PPI	Patient Public Involvement
Professional	Individual with a non-representative role
R	Researcher
Representative	Patient, Public Representative
RCT	Randomised Control Trial
RDG	Research Development Group
SS1	Sibling Site One
SS2	Sibling Site Two
UKERN	UK Epilepsy Research Network

Introduction

This thesis is the product of a PhD studentship based at the University of Liverpool within the Department of Public Health and Policy, funded by the North West Hub for Trial Methodology Research. With a Health Psychology background, a passion for qualitative research and an avid interest in the research question I undertook this challenge. Its purpose was to further current understanding of, and provide recommendations about, the process of patient and public involvement (PPI) in health research, by emphasising the experiences of those involved in the process and how they interpret these experiences. In this short introduction I contextualise the questions addressed in this thesis and outline the information given in the following chapters to provide a framework and guide for this thesis.

Contextualising this thesis

Government policy now advocates that patients and the public must be involved in all stages of the research process (DH, 2006). This commitment to PPI in health research is reflected by the range of UK government funding bodies that now require researchers to specify how they are going to involve PPI representatives in their proposed research, without which information research funding may be declined (2002).

This stance on PPI arises in part from the moral belief that involvement in health care and health care research is a citizen's right within a democratic society (Howe, MacDonald, Barrett, & Little, 2006). This view has been reinforced by the development of activist groups and the social pressure they have generated has helped to establish the rights of the individual in policy and practice (see Section 1.5). Consequently, PPI is often considered, *prima facie*, good beyond question (Dyer, 2004; Florin & Dixon, 2004) and at this level: *"being in favour of better public consultation or more user involvement is rather like being against sin: at a rhetorical level, it is hard to find disagreement"* (Harrison & Mort, 1998, p.66).

As the culture of PPI in research has developed so too has the need to understand the impact of PPI on the research process. Consequently there has been a proliferation of literature discussing PPI that alludes to its possible benefits to the research process (see Section 1.6). However, very little of this literature is based in empirical evidence; the

majority of papers are theoretical or based on anecdotal evidence (see Section 1.6). While little is known about the impacts of PPI on the research process there is even less evidence about the effect of PPI on those involved in the process. Compounding this, the context specific nature of PPI also means that it is difficult to compare across approaches and, therefore, there is limited information for professionals trying to make decisions about how to integrate PPI into their research and the potential pitfalls of which they need to be aware.

Aims and objectives

The principal aim of this thesis was: *To generate a detailed understanding of patient and public involvement in health research.* To accomplish this broad aim I chose to focus on a specific health condition, epilepsy, and the research structures underlying health research in the UK, namely research networks. In order to achieve this, I identified four specific objectives:

1. To describe how PPI was implemented within the specific context of the newly established UK Epilepsy Research Network (UKERN), and research linked to this network.
2. To compare and contrast the theoretical underpinnings of PPI with its practical application in this context.
3. To describe the experiences of the representatives and professionals involved in the PPI process, including their perceptions of the benefits and challenges of PPI.
4. To compare different approaches of implementing PPI, by contrasting the experiences of the professionals and representatives across the different research sites.

Clarifying terms

In Chapter 1 I describe the debate within the literature regarding the labels and definitions surrounding patient and public involvement and explain my choice of terminology (see Section 1.3). However, it is important to briefly define these terms here. I use the term *patient* to refer specifically to those who have experienced disease or illness first-hand (Caron-Flinterman, Broerse, & Bunders, 2005). The term *public* is used to describe all individuals associated with the use of health care, including people who use health and social services, informal carers, parents/guardians, and organisations that represent people

who use services (Staley, 2009). When not specifically denoting one of these two groups, I use the term *representative(s)* as an abbreviation of patient and public representative(s).

I use the label *professional* to describe anyone involved in the research process in a non-representative role for example: clinical academics including doctors and nurses; non-clinical academic researchers; and administrators. Although those involved in research may inhabit several roles and some representatives are also professionals, the distinction between *representative* and *professional* is necessary here in order to designate their roles within the context of this research. Lastly, I define *involvement* as: “*doing research with or by the public, rather than to, about, or for the public*” (INVOLVE, 2012b,p.6).

Overview of this thesis

This thesis is divided into seven chapters covering: background and literature review; methodological considerations; results and discussion. I will now give a synopsis of each of the chapters.

Chapter 1, *Background and literature review* is presented in two parts. The first draws on a general review of the literature to describe the political and moral drivers for PPI, situating it in its historical context. The second presents the findings of a structured literature review into the current evidence base surrounding the impacts of PPI on the research process and those involved in it.

Chapter 2, *Methodological considerations* answers the questions: why focus on epilepsy research and why focus on the UKERN? While accounting for my hermeneutic phenomenological stance, it explains the multi-sited ethnographic method that I used to address the research aims. Methodological considerations such as the data analysis process, ethical considerations and the process of PPI that was undertaken as part of this thesis are also detailed.

Chapter 3, *How PPI is operationalised*, explores the nature of the PPI process in each of the four main research sites. Particular attention is given to the site specific motivations for and decision making processes around PPI, thus starting to address research objective 1 and providing the context for the following three chapters. In the discussion section of this chapter I conclude that there are three key factors that influence the professionals approach to PPI.

Chapter 4, *Professionals' experience and perceptions of PPI*, starts by addressing the professionals' motivation for engaging in PPI, focusing on their understanding of the purpose and benefits. The majority of these benefits are associated with improving the research process to increase how 'useful' or 'relevant' it is. It then goes on to discuss the challenges that professionals experienced, including issues around 'tokenism', 'representativeness', time commitments, disruptions to their academic roles and general worries about getting PPI right.

Chapter 5, *Representative experiences and perceptions of PPI*, shifts the focus to the representatives and their understanding of 'meaningful' involvement, looking in depth at their motivations for involvement and understanding of the potential benefits of PPI. It pays particular attention to the importance the PPI facilitator and how confident the representatives are to contribute in group settings, highlighting six main challenges that representatives experienced.

Chapter 6, *Further consideration of key findings about process and perceptions*, draws together information from the three results chapters to conceptualise 'meaningful' involvement, present a new 'typology' of PPI and identify the strengths and limitations of the different PPI approaches adopted within the four main research sites.

Chapter 7, *Discussion*, brings together the findings from the results chapters in order to compare and contrast representatives and professionals experiences of PPI; and to draw out the main findings. It focus is on issues around: motivations for PPI, meaningful involvement, differences across approaches to PPI, benefits and challenges of PPI and makes clear recommendations about the implementation of PPI in policy and practice. The chapter also addresses some limitations of my thesis and evaluates the choice to use a multi-sited ethnography in this context.

Chapter 1. Background and literature review

1.1 Introduction

In the last two decades there has been a significant drive to increase the involvement of patients in health research (Andejeski et al., 2002), with an emphasis on patients actively contributing to the research process beyond their role as research subjects (Oliver et al., 2008). Over time this initiative has become formalised into policy; for example, the Department of Health Research Governance guidance stipulates that patient involvement should exist at every stage of the research process (DH, 2005). In this two part introduction I first examine what is meant by patient and public involvement (PPI) and situate it in its historical and political context as established by a broad review of the literature. Secondly I describe the findings of a structured literature review that focused on the empirical evidence around the impacts of PPI, highlighting a number of gaps in this literature.

1.2 Part one: PPI's historical and political context

In this part of my literature review, I define who is included in the phrase 'patient and public' and then explore the meaning of 'involvement'. I then go on to describe the moral and political drivers for involvement, as identified in my general review of the literature. This includes both an account of relevant public activist groups and the resulting policy documents. Examining the background and development of PPI is important as it has a direct relationship to the current knowledge base and practice of PPI.

1.3 Who is meant by 'patient' and 'public'?

There is considerable debate within the literature regarding the definition and labelling of patient and public involvement. For example, the labels 'patient', 'consumer', 'service user', 'lay', 'public' and 'client' have all been applied to the individuals consulted and involved in health research (Bastian, 1994). Each label carries multiple, often overlapping, definitions within the literature. Depending on the chosen term and the chosen definition, the individuals included or excluded vary (see Table 1).

Bastian (1994) proposed that this question about labels is: *"not just an argument about words, but about ways of seeing and portraying people and their relationship with the health care system"* (p.11) or, more specifically in the present context, with health research.

Coinciding with this statement, each of the labels has multiple definitions (see Table 1) and invokes a range of connotations and ideological positions (Bastian, 1994; Boote, Telford, & Cooper, 2002). For example, some people are apprehensive about using the term 'patient' as they feel it reflects someone in a traditionally passive position with an inferior status, with implications of dependency and unquestioning compliance, none of which are compatible with active involvement (Herxheimer & Goodare, 1999; Hibbert, Bissell, & Ward, 2002). The terms 'user', 'consumer' and 'public' are the most interchangeable as they tend to be the most inclusive (see Table 1). However it has been argued that 'user' invokes overtones of drug misuse (Herxheimer & Goodare, 1999; Hibbert, Bissell, & Ward, 2002), and 'consumer' is heavily linked with the notion of a commercial relationship, implying that the medical system is a commodity to be bought, which does not sit easily within a publically funded health care system such as that in the UK (Bastian, 1994; Boote, Telford, & Cooper, 2002).

In my studies and in writing this thesis, I have chosen to adopt the phrase 'patient and public', taking the most widely accepted and inclusive definition of the word 'public'. This encompasses all individuals associated with the use of health care, including people who use health and social services, informal carers, parents/guardians, and organisations that represent people who use services (Staley, 2009). In conjunction with this, the word 'patient' will be used to refer specifically to those who have experienced disease or illness first-hand (Caron-Flinterman, Broerse, & Bunders, 2005). Although the phrase 'patient and public' is not universally accepted, I chose this terminology for three main reasons. Firstly it is the most inclusive label, while still placing emphasis on the individual with ill-health. Secondly, it is the description used in current UK policy documents. Thirdly, it the most acceptable terminology to both clinicians and the public (Boote, Baird, & Beecroft, 2010; Dickens & Picchioni, 2011). It is important to note that the terms 'patient' and 'public' are being used to denote roles in a specific situation, not categories of people and it is usual for an individual to fulfil many roles (Herxheimer & Goodare, 1999).

Table 1: Labels and their definitions used in the PPI literature

Author(s)	Definition
Public	
Staley (2009b, p.13)	<ul style="list-style-type: none"> - Patients and potential patients - Informal carers - Parents/guardians - People who use health and social care services - Disabled people - Members of the public who are potential recipients of health promotion programmes, public health programmes and social service interventions - Groups asking for research because they believe they have been exposed to potentially harmful substances or products - Organisations that represent people who use services.
Oliver et al. (2008, p.73)	People whose primary interest in health-care is their own health or that of their family, as users of services or carers; and people representing these groups through community organizations, networks, or campaigning self-help groups.
Consumer	
Andejaski et al. (2002, p.380)	Breast cancer survivors with advocacy experience and the support of a constituency.
Boote, Telford, & Cooper (2002, p.214)	People who receive, or who have the potential to receive, health care... In this interpretation, consumers have been allocated to one of three groups: individuals, local groups and (inter)national consumer organisations.
Oliver et al.(2001, p.19)	The term consumer refers to people whose primary interest in health-care is their own health or that of their family, as past, current and potential patients, users of services or carers, and people representing any of these groups through community organizations, networks, or campaigning and self-help groups.
Patient	
Caron-Flinterman, Broerse, & Bunders (2005, p.2575)	The term 'patients' indicates everyone who has personally experienced diseases or illnesses.
Williamson (1998, p.1374)	Patients are people in clinical relationships with doctors or other healthcare professionals.
Herxheimer & Goodare (1999, p.3)	The people that come to health professionals with an illness or a symptom, for advice and treatment.
Lay	
Ross et al. (2005, p.269)	Lay' because it was seen to encompass involvement through life experience, and be inclusive of service users, carers, patients, clients and citizens.
Charles & DeMaio (1993, p.883)	A common way of differentiating lay from non-lay individuals is to distinguish between providers and non-providers.
Client	
Herxheimer & Goodare (1999, p.4)	A person using the services of a professional person.
User	
Herxheimer & Goodare (1999, p.4)	This is a neutral catch-all term for all those who use or have used any health service, public or private, and is easily extended to include potential users too- that's everybody.

1.4 What is 'involvement'?

Involving patient and public representatives¹ in health research is seen as: *“doing research with or by the public, rather than to, about, or for the public”* (INVOLVE, 2012b,p.6). Regardless of the method of involvement a key component is that there is an active, genuine partnership between the researchers and the representatives (Boote, Barber, & Cooper, 2006; Caron-Flinterman, Broerse, & Bunders, 2005; Rhodes et al., 2002; Williamson, 2001). As PPI requires working with a diversity of perspectives in varying contexts for differing purposes, it has been argued that there cannot be a 'one size fits all approach' (Ross et al., 2005). PPI is often perceived as a continuum from no involvement through to research which representatives initiate, undertake and control themselves (Beresford, 2005). The number of component levels or categories within this continuum is variable dependent on the model.

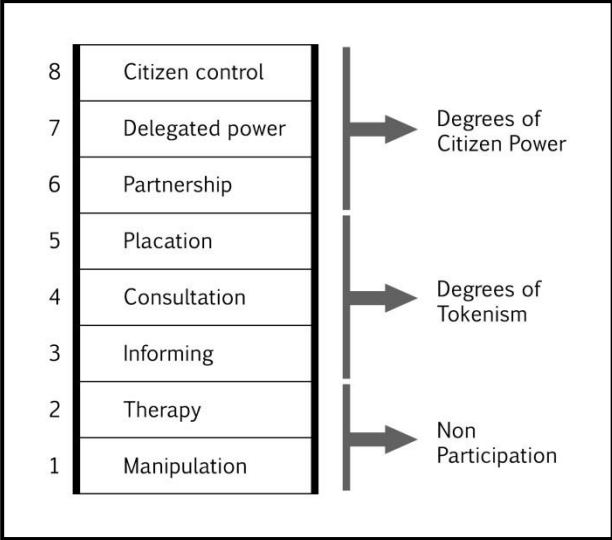
1.4.1 Models of involvement

An early model of involvement was Arnstein's (1969) Ladder of Citizen Participation. Arnstein developed the typology in the context of citizen involvement in urban renewal projects. Nevertheless, she stated that the underlying issues, and consequently the framework, could be applied to any situation where people who traditionally have little power or influence are trying to make others listen and respond to their views. The model equates the level of power the individuals have over determining the end product of any enterprise with their level of involvement. This is represented in the form of a ladder, with each of the eight rungs signifying the degree of influence and power the representatives have (see **Error! Reference source not found.**). The bottom two rungs, Manipulation and herapy, are considered by Arnstein to equate to non-participation, as at these levels professionals do not seek input from representatives, but rather want to teach, cure or bring the representatives to their world view under the guise of involvement. The next three levels, Informing, Consultation and Placation, encompass methods by which representatives have an opportunity to get their opinions across but have no control over whether or not they are subsequently addressed; and so are labelled within the model as Degrees of Tokenism. The final three rungs, Partnership, Delegation of Power and Citizens

¹ Hereon, when not specifically referring to one of these two groups, public and patient representative(s) will be referred to simply as 'representative(s)'.

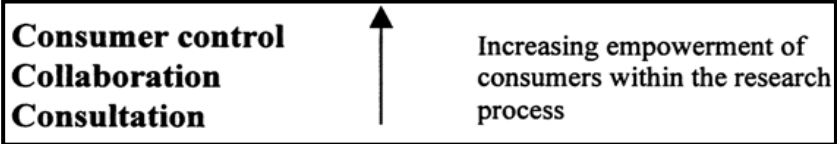
Control are the only levels where Arnstein believed that PPI representatives have a degree of Citizen Power and consequently at least some ability to decide the outcome.

Figure 1: Arnstein’s (1969, p.217) ladder of citizen engagement



Multiple models of PPI have been developed in health research based on Arnstein’s (1969) ladder of participation. The most quoted model of involvement is that by Boote, Telford and Cooper (2002) which they describe as ‘levels of consumer involvement’. Their conceptualisation identifies three categories: Consultation, Collaboration and Consumer control (see **Error! Reference source not found.**).

Figure 2: Boote et al. (2002, p.224) levels of consumer involvement in health research



Consultation includes types of involvement that allow the researcher to obtain representatives’ views. At this level what the representatives say can be influential, but they have no power to ensure the researcher acts on their views (Boote, Telford, & Cooper, 2002). Consultation is largely focused around feedback, for example, asking representatives to review research protocols, participant information sheets and drafts of published papers. This form of involvement is valued as it can be implemented at all stages of the research process using a variety of methods and on a range of scales; for example, drawing on the views of a small group of representatives through a focus group or a large group through administration of a questionnaire (Williamson, 2001).

The Collaboration level is less stringently defined but is typified by an on-going partnership between researchers and representatives in the research process. In collaborative research, representatives have more ownership of the research and can, at least in theory, contribute more directly to the form and direction it takes, for example, by sitting on steering groups. Consumer controlled research is where the representatives hold the power and researchers are brought in as facilitators, with the representatives designing, implementing and disseminating the research. This three level model of involvement became popular as a conceptual framework in health research when it was adopted by INVOLVE, the national patient and public involvement association (Staley, 2009).

In general, other current models of PPI are variations of the 'levels of consumer involvement' model. For example, Minogue et al. (2005) proposed that there are five categories of involvement: consultation; collaboration or partnership; user-commissioned; user-controlled or user-led; and user disseminated. Oliver et al.'s (2008) model subdivides the researcher's degree of engagement in the process in conjunction with the representatives' level of participation, resulting in an eight-dimensional framework. In contrast, Williamson (2001) argued that there are in fact only two types of involvement, Consultation and Partnership. Williamson drew on the same definition of consultation as Boote, Telford and Cooper (2002), then combined user control and collaboration under the label of partnership.

A central theme running through all of these frameworks is Arnstein's (1969) argument that power over outcome is equivalent to level of involvement. It is now starting to be acknowledged in the literature that using this hierarchical criterion of power to denote involvement is an over-simplification. In reality, power does not account for all the dimensions of involvement that might be important, for example, the value of the process of involvement itself or the outcomes of PPI (O'Donnell & Entwistle, 2004; Tritter & McCallum, 2006). Tritter (2009) criticises these models of involvement for: "*assuming that power is finite and that ceding power to one or other parties diminishes the power of the other rather than considering that there are different kinds of power and knowledge and that partnership and collaboration can bring about a better outcome*" (p.279). He goes on to argue that, in addition to issues around framing PPI as a struggle for power, most of the current models do not account for the diversity of people involved or the importance of process as well as outcomes. Building on this, his model of PPI (see Figure 3) conceptualises PPI based on three components: firstly, whether the representatives have an explicit role

(‘direct’ involvement) in the decision making process, or professionals gather representatives’ views and then make the decisions (‘indirect’ involvement); secondly, whether representatives are acting as sole agents (‘individual’ involvement) or as part of a group (‘collective’ involvement); and thirdly, whether representatives help to shape the ‘agenda’ (are ‘proactive’) or work to a pre-existing agenda (are ‘reactive’).

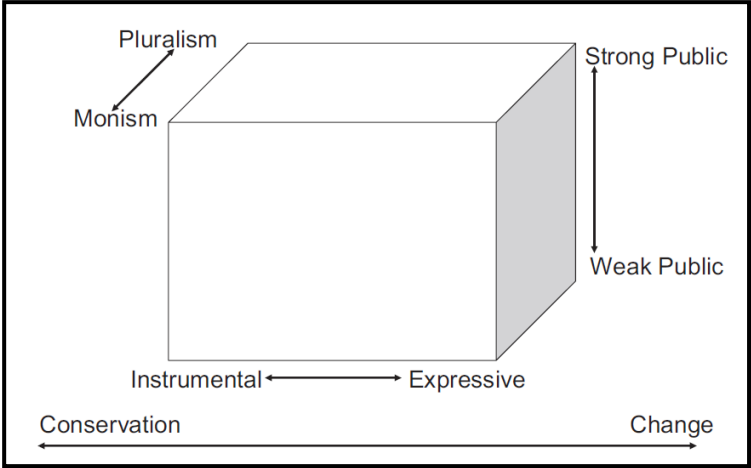
Figure 3: Tritter (2009) ‘A model of involvement’

	Direct		Indirect	
Individual	Proactive	Reactive	Proactive	Reactive
Collective	Proactive	Reactive	Proactive	Reactive

While Tritter’s module of PPI is useful in exploring different components of PPI and expanding the conceptualisation of what involvement is, he does not explain how this model was developed - and I would argue that it is still implicit within his model that power over outcome is a key defining characteristic of involvement.

Gibson, Britten and Lynch (2012) argue that the current models of PPI fail to take into account the cultural, political and social dynamics of involvement. They suggest that emphasis should be placed on how the *interaction* of different types of expertise can allow for new information to be discovered. How this interaction happens, they argue, is dependent on four dimensions which result in new ‘knowledge spaces’. They view the four dimensions as points on a continuum which may move over time and are interdependent (see Figure 4).

Figure 4: Gibson et al. (2012) a Four dimensional view of knowledge spaces



Each of the four dimensions (monism/pluralism, instrumental/expressive, strong public/weak public, conservation/change) draws on different theoretical constructs that are used to describe and position that dimension. Thus, these authors suggest that current PPI methods lead to situations where professional forms of knowledge are more highly valued than the 'experiential knowledge' that representatives may possess, and that representatives may not have the cultural knowledge required to get their opinions across. In such a situation of 'monism' only the professionals' view is taken into account; in contrast 'pluralism' allows for an equal mix of views to be recognised. The authors maintain that PPI can function either to achieve specific aims and goals ('instrumental') or be orientated towards understanding and interpreting representatives' perceptions and experiences as a whole ('expressive'). There are situations where representatives have the ability to influence decision-making ('strong public') and those where the issues may be discussed but they have little chance of influence ('weak public'). Lastly, these first three dimensions operate in a situational context where there may be the need to maintain the current processes ('conservation') or the ability to implement systematic and deliberate change ('change').

The framework is presented as a tool for reflection on current practice and as a means for developing new ways of thinking about involvement. It takes into account the tensions and contradictions involved in PPI. It also allows for PPI to be viewed as on a continuum rather than as a series of dichotomies as proposed by Tritter's (2009) model. It is in essence however, like the others, a heavily theoretically based model.

From my literature review I perceive that the prevailing use of derivatives of Arnstein's model of involvement and the continuing use of power as the primary criterion for defining levels of involvement has limited the ability of researchers to evaluate and make comparisons between the different methods of involvement as, by default, research which takes a consultative approach will be considered inferior to a collaborative or representative led project. The absence of comparative studies and agreed criteria by which to assess PPI means it is not possible to state whether one method of involvement is superior than another (Barber, Boote, & Cooper, 2007), preventing researchers and representatives alike from making informed decisions. Each method is logically associated with different potential advantages and disadvantages. For example, if representatives are involved in designing a study or act as members of funding panels their input might have a substantial influence on the choice of outcome measures or the research process as a

whole (Tritter & McCallum, 2006). However, projects that are led by representatives will be heavily reliant on those representatives having a certain level of interpersonal and professional skills, potentially reducing the number of people capable of being included, which, it could be argued, goes against the principles of PPI as a democratic and representative process (see Section 1.5). In comparison, consultative approaches can involve a broader range of individuals but are more reliant on professional researchers making best use of the information generated. It is important therefore that the method of involvement matches the needs and expectations of all involved (Barber, Boote, & Cooper, 2007; Tritter & McCallum, 2006).

1.5 Evolution of PPI in health research

The justifications for PPI in health research fall under two main categories, the 'political and moral' and 'pragmatic or consequentialist' (O'Donnell & Entwistle, 2004; Telford, Beverley, Cooper, & Boote, 2002; Ward et al., 2009). As the drivers for PPI in the UK have their basis more in notions of policy and morality (Boote, Telford, & Cooper, 2002) this will be discussed first, followed by the more recent focus on the pragmatic justifications (see Section 1.6).

There are three broad political and moral drivers of PPI. Whilst these drivers will be presented separately to allow each to be discussed in depth, they are intrinsically linked. The first is the underpinning moral and ethical position linked to the belief that involvement in health care and health care research is a citizen's right within a democratic society (Howe, MacDonald, Barrett, & Little, 2006). The second to be discussed is the development of activist groups and how the social pressure they generated helped to establish the rights of the individual in relation to policy and practice. The third driver, political developments as reflected in policy documents, will be explored to demonstrate how policy has responded to, and in turn, enabled activist groups to develop PPI.

1.5.1 Ethical and moral underpinnings

The moral and ethical arguments for PPI in research flow from the belief that individuals whose lives and bodies may be affected by research should have a say into what and how research is undertaken (Bastian, 1998; Boote, Telford, & Cooper, 2002; Caron-Flinterman, Broerse, & Bunders, 2005; Staley, 2009b). In a democratic society, involvement in health research is considered a right of the public, especially in relation to publicly funded

research and a publicly funded health service wherein representatives can be seen as stakeholders (Dyer, 2004; Florin & Dixon, 2004; Ward et al., 2009). Bastian (1998) also suggests that the ethical validation of PPI addresses ideas of community responsibility, social justice and accountability.

Harrison and Mort (1998) argue that at this moral level it is hard to disagree with the principle of involvement, suggesting that: *“being in favour of better public consultation or more user involvement is rather like being against sin: at a rhetorical level, it is hard to find disagreement”* (p.66). This was also highlighted by Arnstein (1969) who typified the concept by stating: *“the idea of citizen participation is a little like eating spinach: no one is against it in principle because it is good for you”* (p.216). Consequently, PPI is often considered, *prima facie*, good beyond question (Dyer, 2004; Florin & Dixon, 2004). These right-based arguments have been used to advocate for PPI in research (O'Donnell & Entwistle, 2004) and as such PPI may be seen as a goal in and of itself (Bastian, 1994). Despite the importance of this ethical stance, advocates of PPI are cautioned against stating the moral case as the sole justification of PPI in research, as this may not be enough to motivate mainstream researchers to involve representatives in their work (Beresford, 2005).

It has been proposed that the moral and ethical stance of any culture both feeds into and is generated by its government's policies (Shore & Wright, 1997). This seems particularly evident in the development of PPI. The following sections describe how public activism drove the development of health policies that, combined with the moral arguments, were among the main drivers for PPI in health research.

1.5.2 Development of public activism

“A social movement does not imply one great monolithic structure or a single interest group: it is made up of many parallel, and not necessarily concerted, actions in a community, and it should indeed ‘move’ and seek to create social change. Some of the key characteristics of a social movement are that there are some beliefs that are generalized throughout and that the movement remains politically alive, renewing itself and passing on its beliefs and heritage to new generations of activists.” (Bastian, 1998, p.14)

Bastian's (1998) multi-level and historically developing process of social change is reflected in the many different activist movements that have been regarded as the impetus for PPI. The lessons learnt by one group trying to change policy and society are cross-fertilised and used by other groups until the combined pressure from all the groups leads to overarching change. Most of the literature situates the advent of PPI in the social movements in the late

20th century. Each of these can trace their lineage back to the freedom movements at the turn of the 18th century when increased literacy and the political acknowledgment of the rights of the individual led to more cohesive and sustained activism, for example, the abolition of slavery and the independence movements of European colonies (Bastian, 1998). The industrialisation of Western Europe in the late 18th early 19th century is also regarded as a key time point in the history of activism in general, as the consequent start of Trade Union activism for workers' conditions of employment and health and safety in the work place demonstrated the efficiency of powerful and effective advocacy (Webster, 1990).

The feminist, civil rights, consumerist, acquired immune deficiency syndrome (AIDS) and disability movements of the late 1960s and early 1970s have all been credited as the origin of more recent advances in PPI (Bastian, 1998; Beresford, 2005; Fisher, 2002; Frankham, 2009; Lupton, 1997). However, my review of the literature suggests that claims for their role in stimulating PPI are often vague and unclear. Many authors state that these movements were the catalysts for PPI, without supporting or justifying this claim. This is especially true with regard to the link between the feminist movement and PPI. Adopting Bastian's (1998) view on the need for many overlapping social pressures to result in social change, I maintain the argument that the current focus on PPI results from a combination of the philosophies and activities of these movements.

The feminist and civil rights movements are credited with shaping: *"a generation's consciousness of the role that gender, race, ethnicity and class play in constructing knowledge and legitimating 'knowers'"* (Brisolara, 1998, p.26). Feminists were the first group of researchers to focus on the importance of 'unalienated knowledge', placing the person and their subjective view of their own experience at the centre of the research process (Morris, 1992). This shift away from an 'objective', medical model to a more person-centred approach resulted in the development of new research paradigms and methods (Keith, 1992) and contributed to creating a society that was more amenable to the importance of different types of knowledge. In addition, the feminist movement in the 1960s and the research it generated began to challenge medical professional values, and more critically, its professional claim to medical expertise (Coulter & Fitzpatrick, 2000).

The principles of consumerism also started to penetrate the health care system in the 1970s, providing an additional range of challenges to the dominant medical model (Coulter

& Fitzpatrick, 2000). Pickstone (2000) reported that consumerism was driven by the emphasis in the 1960s on choice of lifestyle, especially in relation to sexual behaviour and reproduction. Consumerism was actively encouraged in the 1970s by popular medical journalism, private health companies, pharmaceutical companies and leisure companies (Pickstone, 2000). The consumerist model of health is based on the principle that health care should be considered a commodity to be bought and sold (Lupton, 1997). Within this model, medical practitioners are seen as competitive providers of their medical expertise. If they are overpriced or provide an unsatisfactory service, the patient will choose an alternative provider. The theory was that if this model was applied to health care it would facilitate increased quality, consumer choice and optimal pricing (Lupton, 1997). Consumerism emphasises choice, responsibility and empowerment of the patient and promotes the view that the power between health care providers and patients should be more evenly distributed (Ward et al., 2009). At the centre of this model is the assumption that the modern patient has greater access to information, is more open to challenging clinician authority and is as capable of navigating a consumerist health system as they are in other aspects of their lives (Goode et al., 2004; Harrison & Moran, 2000). It has been suggested that the consumerist movement also allowed some patient groups to evolve into consumer groups who could actively lobby for services and research that they deemed important (Pickstone, 2000).

It is highlighted in the literature that there is an underlying conflict between a consumerist health model and a publicly funded health service, such as the one in the UK (Newman & Vidler, 2006). Given that in this situation no one can ever be a 'real' consumer since they are not paying directly for the service, they may be an unwilling consumer, or medically incapable of making a competent decision. Even putting these factors aside, patients may have no choice over their healthcare provider due to an absence of 'real' competition for most services (Calnan & Gabe, 2001; Harrison & Moran, 2000; Newman & Vidler, 2006). The question of whether or not patients and practitioners really expect or want the medical system to function in a similar fashion to a commercial business or whether it has its own separate place in British society has also been repeatedly raised (Harrison & Moran, 2000; Newman & Vidler, 2006; Rhodes & Nocon, 1998).

The development of consumerism within health care provision has been mirrored by a similar, if slightly delayed rise in the idea of consumerism in health research (Henderson & Peterson, 2002; Hill, 2007) leading to the emergence of the 'research consumer' (Ward et

al., 2009). As with health care, consumerism in research has turned research into a competitive commodity that has to be responsive to consumer needs. However, the underpinning notions of choice within the consumerism model beg similar questions in relation to research as in relation to those raised in health care (Ward et al., 2009).

Whilst the consumerist model of health care provision and health research has not gained full acceptance in the UK, in order to respond to societal demands, improve services and increase patient satisfaction, the health profession has had to reconceptualise what it means to be a patient and renegotiate issues of power (Coulter & Fitzpatrick, 2000; Harrison & Moran, 2000; Newman & Vidler, 2006). Consequently consumerism maybe considered one of the main influences on health and health research policy (Crinson, 1998).

In the 1970s AIDS activists developed creative, flamboyant campaign techniques instead of following the established rules of lobbying (Sepkowitz, 2001; Williamson, 2001). These methods ranged from wearing red ribbons, drug buyers' clubs and telephone 'zaps' (the jamming of switchboards) through to aggressive civil disobedience. These activists raised questions as to whether AIDS funding was being apportioned appropriately; consequently the USA's Institute of Medicine recommended broader public input into decisions about the allotment of research funds (Sepkowitz, 2001). In addition, perceived government inactivity and delay with regards to prevention or treatments resulted in AIDS groups self-funding research designed to impact on policy, treatment and testing of new drugs via clinical trials. Subsequently gay men had unprecedented oversight and input into AIDS research, leading AIDS campaigners to be viewed as one of the original, successful models of PPI in health research (Bastian, 1994; Berridge, 2000). This success subsequently influenced the approach of many other patient groups including those for patients with breast cancer, Parkinson's disease and Alzheimer's disease (Andejaski et al., 2002; Berridge, 2000; Sepkowitz, 2001).

While the late 1960s and early 1970s saw the politicisation of disability activists (Barnes, 2003), a key turning point for PPI was the redefinition of disability in 1976 by the UK Union of the Physically Impaired Against Segregation (UPIAS). This group made a significant distinction between physical impairment and the 'disability' caused by social context, stipulating that physical impairment was the medically defined condition that an individual has, and that: *"disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society"* (UPIAS, 1975, p.14).

This social-political interpretation is described as the 'social model of disability' and resulted in the growth of emancipatory and participatory research, with its followers emphasising the importance of sharing control of the research process with the people who are the most influenced by it (Frankham, 2009).

The underlying principles of the social model of disability and emancipatory research methods connect many subordinate or minority groups who can argue that their positioning in society is not just a consequence of their sexuality, ethnicity, mental health or medical condition, but rather of how others are conditioned to respond to them and how social policy impacts on them (Frankham, 2009; Lewis, 2004). This argument has shifted the focus of attention away from individual deficits and onto social structures and how these need to be adapted to enable the proper participation of disabled people in society (Oliver, 1992). In addition, the increased emphasis on valuing experiential knowledge, combined with the improved lobbying techniques developed by AIDS campaigners at a time when the medical profession was reassessing the role of the patient as a consumer, resulted in the acknowledgment of the importance of a patient and public focused health service and the need to have PPI in health research (Beresford, 2005; Fisher, 2002; Frankham, 2009). In recent years, social activist pressures have become more unified with the development of groups such as INVOLVE. INVOLVE is a national advisory group members of which describe themselves as: *"specialists in public participation; bringing institutions, communities and citizens together to discuss, decide and reshape the things that matter to them. INVOLVE makes a practical difference to democracy by delivering, researching and promoting high quality public participation processes"* (INVOLVE, 2012a). This arguably allows for a more cohesive and sustained pressure on issues related to PPI than is achieved from the disparate efforts of individual activist groups.

The PPI agenda was given considerable momentum as a result of evidence of serious clinical and service failings in the NHS, highlighted by a number of high-profile inquiries, including those relating to: Bristol Royal Infirmary, Dr Shipman, Maidstone and Tunbridge Wells Hospital, Alder Hey Children's Hospital and the Mid Staffordshire NHS Foundation Trust (Ocloo & Fulop, 2011). Some of these inquiries involved specific individuals - such as the Shipman inquiry, which investigated the activities of the general practitioner, Dr Harold Shipman, who it is believed to have murdered at least 215 of his patients between 1974 and 1998 (Baker, 2004). Others, such as the Alder Hey inquiry, explored NHS institutional practises around the unauthorised removal, retention, and disposal of human tissue. These

inquiries were frequently fought for by patients harmed by patient safety incidents and their families; and the conclusion from them was that active PPI is vital to ensure similar failings do not happen again (Ocloo & Fulop, 2011). For example, the Bristol inquiry into the high mortality rate of babies undergoing heart surgery at the Bristol Royal Infirmary urged doctors to include patients as active participants in their own care to help ensure patient safety, reduce complaints and litigation, encouraging patient self-reliance, quality improvements and 'accountability' (Coulter & Dunn, 2002). The Mid-Staffordshire review into substandard care and staff failings at two hospitals in Mid-Staffordshire between January 2005 and March 2009, identified six key recommendations for improving services focused on PPI, emphasising the importance of responsive 'real time' data collection surrounding complaint procedures. The argument was made that patient experience information can demonstrate that even when an organisation is performing well overall, more detailed feedback about patients' experiences may demonstrate that some wards, departments or services are underperforming (Thome, 2009). Smith (1998b) highlighted how these very public 'dramas' held the attention of both members of the public and medical staff in a way that policy documents did not, affecting the trust between patients and doctors and acting as a catalyst for the development of PPI in the UK health system.

In response to the varied and sustained social pressure for inclusion, the British government started to incorporate PPI into its policies. The following section describes how these policies have changed and developed over the last 30 years, but are still considered to be lacking in detail and not fully justified.

1.5.3 Development of UK policy on PPI

The Griffiths Report (DH, 1983) is credited with being the first UK health policy document to address PPI, albeit in a rudimentary form (Boote, Telford, & Cooper, 2002). This report resulted in general managers being appointed at each level of the NHS. Part of their role was to assess patient/consumer satisfaction with services and be responsive to the feedback they received (Calnan & Gabe, 2001). Before this there had been little or no emphasis on patients' perspectives or levels of satisfaction. Instead, the NHS was run by teams of practitioners with doctors and nurses sharing managerial responsibilities (Kelleher, Gabe, & Williams, 1994). The perception of the public as consumers was solidified by the 1989 White Paper 'Working for Patients' which resulted in the introduction of an 'internal market' within the NHS (DH, 1989; Flynn, 1991). This separated service

providers from Commissioners and is recognised as attempting to introduce a degree of customer choice (Rhodes & Nocon, 1998). Patient satisfaction surveys were seen as legitimising managers' claims that they understood the needs of the patients. However, the content of the surveys was often considered superficial (Calnan & Gabe, 2001).

The consumerism paradigm was still evident as a underlying force in the early 1990s, as reflected in the 'Patient's Charter' (DH, 1991) and 'Local Voices' (DH, 1992) policy documents. The Patient's Charter was intended to make the health service more responsive to the needs of its consumers by informing them of their rights and the level of service they could expect (Florin & Dixon, 2004; Rhodes & Nocon, 1998). The types of rights identified in the document included admission to hospital within two years of being put on a waiting list, detailed information about local health services and the right for all complaints be followed up and dealt with appropriately (Calnan & Gabe, 2001). The Local Voices document encouraged managers to consult with their local populations when making purchasing decisions (Calnan & Gabe, 2001; Rhodes & Nocon, 1998) and was perceived to give official government support for involving the public in NHS processes (Harrison & Mort, 1998). Rhodes and Nocon (1998) highlighted that these two documents are often confused with each other, but the key difference is that the Patient's Charter was about rights for people at the point of interaction with the NHS, whereas Local Voices addressed PPI in a much wider context. A consistent criticism of the policies set out in both documents was that they did not have to be enforced and there was no statutory obligation to pursue them, so they were often not implemented. They were also perceived as mechanisms by which to monitor levels of service rather than as means of addressing patient priorities (Calnan & Gabe, 2001; Rhodes & Nocon, 1998). In addition, the Patient's Charter targets were considered to be ambiguous and ineffective, and resulted in more power being given to managers rather than to patients (Boote, Telford, & Cooper, 2002; Calnan & Gabe, 2001).

Newman and Vidler (2006) argued that when New Labour came into power in 1997 and issued the White Paper 'The New NHS: Modern, Dependable' (DH, 1997) there was a return to a more paternalistic approach in health policy. It has been suggested (Boote, Telford, & Cooper, 2002; Rhodes & Nocon, 1998) that this was a calculated strategy to reassure health professionals at a time of great job uncertainty brought about by the 'internal market', and to address more pressing concerns for public accountability. While the White Paper referred to the value of PPI, it did not discuss how and why it should be addressed. The importance of PPI was re-emphasised later with the document 'A first Class service: Quality

in the new NHS' (DH, 2000) which highlighted the need to engage the public in an active relationship with professionals in all areas of the NHS. The emphasis was now on partnership and cooperation as opposed to consumerism in relation to PPI (Calnan & Gabe, 2001).

In terms of health research policy more specifically, PPI in research was first acknowledged as important in 1991 with the launch of the NHS Research and Development strategy (Boote, Telford, & Cooper, 2002), an agenda that became increasingly important. Thompson (2010) identified three key policy documents that specifically referred to and proposed development of public involvement in research: 'Patient and Public Involvement in the NHS' (DH, 1999), 'The Research Governance Framework for Health and Social Care' (DH, 2005) and 'Best Research for Best Health' (DH, 2006). The 'Patient and Public Involvement in the NHS' (DH, 1999), document stated that:

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

While this was a substantial policy development for the promotion of PPI, the rationale informing this directive was unclear, as were ways in which the public might be involved in the research and development process (Thompson, 2010). Subsequently this was expanded upon in 'The Research Governance Framework for Health and Social Care' (DH,2005) and 'Best Research for Best Health' (DH, 2006), the latter of which specified that:

"... patients and the public *must be involved in all stages* [my emphasis] of the research process: Priority setting, Defining research outcomes, Selecting research methodology, Patient recruitment, Interpretation of findings, Dissemination of results." (DH, 2006, p.34)

The 'Best Research for Best Health' report (DH, 2006) also provided a brief rationale for public involvement in research, stating that it increased the applicability, relevance and reliability of research. However, the report gave no evidence to support these claims and like 'The Research Governance Framework for Health and Social Care' (DH,2005) has been criticised for not providing a specific definition of PPI (Fudge, Wolfe, & McKeivitt, 2008; Thompson, 2010). The reports also heavily focused on PPI as a quality issue, failing to address the multiple motivations for PPI (Fudge, Wolfe, & McKeivitt, 2008). Despite these limitations, it is now government policy that researchers involve representatives in all stages of the research process. This commitment to PPI in research is reflected in the range of government funding bodies that now require researchers to specify how they are going to involve representatives in their proposed research, without which information, research

funding maybe be declined (Boote, Telford, & Cooper, 2002). Thus, it is now politically and financially wise for researchers to engage in PPI, irrespective of the moral or practical motivations (Telford, Beverley, Cooper, & Boote, 2002; Ward et al., 2009).

1.6 Part two: focused literature review of PPI impacts

While the impetus for PPI stems from the political and moral drivers discussed, it is now acknowledged that there is a necessity for a meaningful evidence base around the consequentialist aspects of PPI (Beresford, 2005; Boote, Telford, & Cooper, 2002). This evidence is needed to allow for a critical assessment of the costs and benefits of PPI to the research process, to facilitate best practice and to motivate researchers who are more resistant to implementing PPI (O'Donnell & Entwistle, 2004). In order to establish what empirical evidence is available regarding the impacts, costs and benefits of PPI on the research process and those involved, I conducted a second more focused review of the literature. Before outlining the findings of this review, I will briefly describe how it was conducted.

As explained in 1.5.2 INVOLVE is a government funded organisation: *“to support active public involvement in NHS, public health and social care research”* (INVOLVE, 2012a). In 2010 INVOLVE had established an online library of 175 references, articles and reports that look at the impact, nature and extent of public involvement in research (INVOLVE, 2010). This detailed library was the starting point for my focused literature review. I combined the INVOLVE references with database searches, reference and author tracking, and using all possible labels of PPI, I generated a master list of 229 references. As a substantial amount of information on PPI is published in reputable grey literature (Rummery, 2009; Telford & Faulkner, 2004), these references did not just include peer reviewed articles. Although my review was not a systematic review in the ‘pure’ sense, it was structured and extensive. Once this master list had been generated I developed a strategy for determining the relevance of the references, to establish which should be included in my review. The forty most cited references were selected (taking into account their year of publication), to ensure that the most influential references were addressed. I also included 19 literature reviews as their findings represented a much larger evidence base. References that were based on primary evidence sources, focused on health research networks or the experiences of those involved were deemed particularly relevant and were also included. Consequently 63 articles were selected to be explored and summarised, to

examine the current evidence of the impact of PPI in health research. Using Nelson et al's (2011) approach as a guide, I paid particular attention to the focus of each paper, the main findings, strengths and limitations (see Appendix 1). I updated the literature review in November 2012 with the aid of INVOLVE'S updated bibliography (INVOLVE, 2012c) and additional literature searching. This resulted in a final master list of 266 references with 74 references included in the review (see Appendix 1).

Despite the extensive literature discussing PPI, I found there to be extremely limited empirical evidence to support claims of its impacts. The majority of the papers were theoretical or based on anecdotal evidence. This same observation was repeatedly reported in the PPI review articles (Boote, Telford, & Cooper, 2002; Minogue et al., 2005; O'Donnell & Entwistle, 2004; Oliver et al., 2008; Staley, 2009b). Overall however, the same claims of PPI impacts are consistently reported within the literature (Staley, 2009) and can be placed into three discrete categories: impact on the research process, impact on the professionals and impact on the representatives. Each of these will be discussed in turn in this section. When discussing the potential effects of PPI it is necessary to be mindful that some aspects of implementing PPI maybe context and condition specific, for example, issues surrounding involving someone in a wheel chair may differ to those of involving someone who has had a stroke.

1.6.1 Effects on the research process

Trying to unpick the limited evidence about how PPI can influence the research process is difficult as many of the arguments are overlapping and vague. Improved relevance, credibility and acceptability appear to be the most commonly listed benefits (Caron-Flinterman, Broerse, & Bunders, 2007; Elberse, Caron-Flinterman, & Broerse, 2011; Fisher, 2002; O'Donnell & Entwistle, 2004; Popay & Williams, 1996; Rhodes et al., 2002; Wright et al., 2007; Staley, 2009a). The experiential knowledge that representatives contribute gives credence to their ability to make judgment calls on how relevant the purpose and outcomes of a research project are to the targeted population. This is believed to increase the project's usability to both its participants and the wider research community. This perceived usability in turn gives the research increased credibility and acceptability, making it more likely to influence practice and improve healthcare (Oliver et al., 2008). While this intuitively makes sense, there is limited evidence to support these claims. It can be argued

that at this conceptual level just the perceived presence or endorsement from patients and the public might have a similar result to actual involvement.

There are more tangible ways in which PPI may positively impact on the quality of research design and, in turn, its relevance. It has been suggested that PPI can improve the clarity of participant information, removing jargon and making it more salient to potential participants (Boote, Baird, & Beecroft, 2010; Hanley et al., 2001; Minogue et al., 2005). Representatives' knowledge can improve outcome measures in terms of quality, usability and applicability (Boote, Baird, & Beecroft, 2010; Faulkner & Thomas, 2002; Fisher, 2002; Rhodes et al., 2002; Staley, 2009b). PPI can facilitate more representative sampling as it can facilitate access to 'hard to reach' populations through PPI networks (Coupland & Maher, 2005). An additional benefit is the potential to increase recruitment; this is particularly significant for clinical trials that, historically have cited failure to recruit as a primary reason for non-completion (Iliffe, McGrath, & Mitchell, 2011; McDonald et al., 2006; Watson & Torgerson, 2006; Wyatt et al., 2008). However, evidence of increased recruitment is largely anecdotal as it is difficult to measure. It has also been suggested that PPI can expedite ethical approval and data collection, shortening the time frame of the research (Coupland & Maher, 2005; Elliott, Watson, & Harries, 2002; Wight et al., 2006). Lastly, PPI is claimed to broaden opportunities for dissemination, increasing the impact of the research (Wight et al., 2006; Wyatt et al., 2008; Staley, 2009a). Therefore PPI is regarded as having a potential to benefit all stages of the research process. However, some researchers have expressed concerns that PPI will negatively impact the relevance of research as they feel representatives may not have a holistic perspective and, being partisan, may not be able to judge the importance of a project (Caron-Flinterman, 2005; O'Donnell & Entwistle, 2004).

Reporting of negative impacts of PPI on the research processes are limited and are mostly described as barriers or challenges to implementing PPI rather than negative impacts on research (Simpson & House, 2002). I submit that this gap in the literature is due to a combination of a general lack of evaluation of PPI and the political environment in which this type of research takes place. Added cost, time and complexity of PPI are the main barriers to its implementation reported in the literature (Boote, Baird, & Sutton, 2011; Trivedi & Wykes, 2002). Room hire, training, additional administration, time and travel reimbursement are all potential costs of PPI that are often not taken into account during resource allocation (Mitton et al., 2009). This is compounded by the fact that researchers are encouraged to implement PPI at the application stage which means funding for PPI, at

least in the early stages of a project, is likely to be limited. Administration, recruitment, training and support of representatives all require time and resources commitments that are not part of the traditional research process. Also representatives might have difficulties working within the traditionally tight academic and funding body timeframes and structures as a result of other commitments or their health condition (Elliott, Watson, & Harries, 2002; Mitton et al., 2009; Rhodes et al., 2002; Wright et al., 2007). Time and cost constraints, combined with the additional complexity of working with another stakeholder group, could act as deterrents for researchers considering involving patients and the public. They are not however, implicitly detrimental to research design and outcomes.

1.6.2 Effects on representatives

Only a handful of the papers reviewed provided empirical evidence on the effect of being involved in research on the representatives. The majority of impacts are focused around a positive change in representatives' self-perception (Newell & South, 2009). Representatives report increased confidence in their own capabilities and influence, feeling valued, improved self-esteem and an overall sense of well-being as outcomes of their roles (Minogue et al., 2005; Newell & South, 2009). They also value gaining knowledge of their condition and the research process, alongside new skills and experiences (Minogue et al., 2005; Newell & South, 2009; O'Donnell & Entwistle, 2004; Rhodes et al., 2002). Additionally, the opportunity to interact with other people with a similar condition not only provides them with a chance to exchange information but also to establish new forms of peer support (Minogue et al., 2005; Rhodes et al., 2002). Analogous with other research in this area, research on the effect of PPI on representatives was focused on the positive aspects of involvement rather than the challenges. Rummery (2009), however, suggests that some representatives found increased information on their condition elevated their anxiety levels and Newell and South (2009) highlighted that some representatives had concerns about the perceived level of responsibility PPI brought. It is evident from this that there is a need for further research to understand the experience of PPI on representatives.

1.6.3 Effects on professionals

While there is limited evidence about the effects of PPI on the research process and the representatives there is even less on the effect on the professionals² (Staley, 2009b). This is

² I use the term 'professional' to encompass anyone who is involved in the research process not as a patient or public representative.

surprising as it is professionals who implement and facilitate PPI and without their support, PPI is unlikely to occur.

Some professionals have been found to appreciate the PPI process as an opportunity to interact with representatives outside of their normal clinical roles. This different form of interaction has been found to help researchers learn about the culture of their participants (Elberse, Caron-Flinterman, & Broerse, 2011), increase their social awareness of local communities (Newell & South, 2009), connect to the 'real world' (Lindenmeyer et al., 2007), develop conflict resolution systems and skills, and result in a more positive attitude towards their patients (Coupland & Maher, 2005).

Coupland and Maher (2005) recognise both the benefits and challenges to professionals of the 'blurring' of clinician-patient, researcher-participant roles that PPI can bring. This blurring provides new opportunities for learning and developing systems, but can be disconcerting for the individuals involved. Some professionals feel that by placing increasing emphasis on representatives' knowledge that there is a shift in research ownership away from the professional (Faulkner & Thomas, 2002). Professionals have identified concerns about 'who' they should involve, the abilities of the representatives and how to involve them. The 'who' questions are not just focused on labels and breadth of experience (see Section 1.3) but how to ensure that representatives are 'representative' of the target group (Entwistle, Sowden, & Watt, 1998; Entwistle et al., 1998; Rhodes et al., 2002). Caron-Flinteman (2005) identified eight key concerns that researchers may have about involving representatives:

“Lack essential knowledge about research issues and procedures; do not speak nor understand scientific language, are unable to put their own questions and demands into a scientific context; have unrealistic expectations of scientific research; are strongly influenced by the media; are unable to abstract from their own individual situation; have difficulty to think in long-term targets; and/or are only interested in subjects concerning care or social issues.” (p. 254)

Paradoxically, representatives about whom professionals do not have such concerns may be considered atypical of the general population and therefore not truly 'representative' (Lindenmeyer et al., 2007).

1.7 Summary

My review of the literature suggests that PPI in health research was originally driven by activist groups and government policies. Combined with the strong moral and ethical arguments and guidelines from funding bodies, PPI is becoming mandatory in health research. However, there is currently little in-depth empirical evidence on the impact of PPI and the evidence that is available appears to be limited as it often overlooks negative or challenging aspects of PPI.

I conclude there is a need for comparative studies across different approaches to PPI involvement to help researchers make informed decisions and to provide insights into the effects of PPI on research. There is also a need to better understand the experiences of the people involved in PPI, both professionals and representatives. This would allow potential challenges to be addressed from the outset, improving the PPI experience and consequently the likelihood of PPI being successfully implemented. Also, PPI might be more appropriately facilitated if the different groups had the opportunity to understand their counterparts' perspectives so that they gain an insight into each other's mindsets and the constraints they each operate under. My research aimed to address some of these issues by developing a detailed understanding of PPI involvement within the context of health research, with a focus on a specific condition, epilepsy. Chapter 2, Methodological considerations, more explicitly states my research aims and objectives, describing and justify the process I undertook to achieve them.

Chapter 2. Methodological considerations

2.1 Introduction

Through exploring the literature as discussed in Chapter 1 I reached the conclusion that a more in-depth understanding of the PPI process was needed. The purpose of this chapter is to describe the multi-sited ethnographic approach that I adopted to achieve this. To provide a framework for the project, I focused on a specific health condition, epilepsy, and a particular research context, the recently established 'UK Epilepsy Research Network' (UKERN) and two trials hosted by it.

In this chapter I first describe the research aims and epistemological stance that underpins this research. Building from this I explain my decision to use a multi-sited ethnographic approach, focusing on the specific methods used, including details of site selection, data collection and how ethical considerations were addressed. Within this I also provide some pertinent information about epilepsy research to place my findings in context. Lastly I discuss how the principles of PPI were incorporated into this research, to ensure that it was directly informed and guided by the views of representatives.

2.2 Research aims and objectives

The principal aim of this thesis is: *To generate a detailed understanding of patient and public involvement in health research.* To accomplish this broad aim I chose to focus on a specific health condition, epilepsy, and the research structures underlying health research in the UK, namely research networks. In order to achieve this, I identified four specific objectives:

1. To describe how PPI was implemented within the specific context of the UK Epilepsy Research Network (UKERN) and research linked to this network.
2. To compare and contrast the theoretical underpinnings of PPI with its practical application in this context.
3. To describe the experiences of the representatives and professionals involved in the PPI process, including their perceptions of the benefits and challenges of PPI.
4. To compare different approaches of implementing PPI, by contrasting the experiences of the professionals and representatives across the different research sites.

2.3 Theoretical orientations

It is accepted in qualitative research that an investigator's theoretical beliefs about the nature of reality shape how they see the world, linking the researcher to a bundle of assumptions and practices that they utilise when choosing and implementing methods of inquiry (Crotty, 1998; Denzin & Lincoln, 2011). To fully explain my choice of methods I am first going to describe my views on the nature of 'knowledge' and my relationship to it.

Through my Undergraduate and Master's degrees I had developed a basic understanding of different theoretical orientations. In order to gain both a more nuanced and broader understanding of different qualitative methodological approaches and methods, in the first six months of my PhD I completed the University of Liverpool's module 'Epistemological and Methodological approaches to Qualitative Research in Medicine'. This postgraduate module explored ontology, epistemology, methods and methodical approaches in the context of the Social Sciences. It explored the strengths and limitations of different theoretical orientations and placed them in their historical context. Starting with 'historical perspectives on science, rationality and method: the empiricist perspective' the course detailed the development of qualitative research, exploring topics such as: Positivism, Phenomenology, Ethnomethodology, Symbolic Interactionism, Social Constructionism and the implications of Postmodernism. Independently I explored additional theoretical orientations such as Critical Realism (Bygstad & Munkvold, 2011) and Pragmatism (Cameron, 2011). Table 2 summarises the key elements in each of these orientations. As these orientations all take a postmodernist view I did not perceive them all as discrete positions. Rather I viewed them as overlapping; it is where they place emphasis and focus that distinguishes them from each other. Given this overlap, my selection of chosen orientation was made at a more intuitive level, in terms of which seemed to me to suit my purpose; rather than through a structured process of weighing the advantages and disadvantages of each in this context. I concluded that Social Constructionism and Phenomenology offered theoretical orientations which best aligned with my research into the process, experience and context of PPI (see Section 2.2).

Table 2: Summary of potential theoretical orientations

Theoretical Orientation	Summary
Phenomenology	Concerned with understanding and describing how things are subjectively experienced and interpreted by those involved (Denscome, 2007).
Ethnomethodology	Focuses on how members 'do' social life, aiming to document how they construct and sustain social objects (Denzin & Lincoln, 2011).
Symbolic Interactionism	Biased on three premises (Flick, 2009a): <ol style="list-style-type: none"> I. how we act towards 'things' depend on the meaning we ascribe them II. meanings are derived from social interactions between people III. these meanings are adjusted through an interpretive process
Social constructionism	Stipulates that knowledge is not found or discovered but made. We develop concepts, models and schemas to make sense of experience, continually testing these constructions in the light of new information and experiences (Denzin & Lincoln, 2011).
Critical Realism	Underlined by the beliefs that (Bygstad & Munkvold, 2011): <ol style="list-style-type: none"> I. the 'real world' exists independent of our knowledge of it. II. we then interpret this reality III. some interpretations reflect reality better than others; there are logical ways to assess the validity of the interpretation
Pragmatism	Importance is placed on the 'practical' rather than the 'abstract'. The value of any theory can only be judged by how well it can be applied in relation to practical needs and how well it functions in practice (Denscome, 2007).

From a Social Constructionist perspective, knowledge is based against a backdrop of shared understandings, practices, experiences and language (Schwandt, 2000). Social reality is seen as inter-subjective, constructed between people through shared language, history and culture (Berger & Luckmann, 1991); therefore what exists or represents 'reality' is what we perceive to exist (Burr, 2001; Green & Thorogood, 2004). Explanations offered by social constructionism are often framed in terms of the dynamics of social interaction, with emphasis placed on process and context rather than structures (Burr, 2001). As PPI is context specific, and my research aimed to focus on the 'processes' of PPI, social constructionism seemed, initially to fit my purpose. However, one of the key assumptions within social constructionist approaches is that knowledge cannot be separated from socio-linguistic practices. Consequently language and how it is used to construct reality is a key component within social constructionist research (Burr, 2001; Gergen, 1996; Nightingale &

Cromby, 1999). My research was not aimed specifically at focusing on how language is used to construct the 'reality' of the PPI process, but rather at exploring participants' experiences and perceptions of their 'subjective' PPI experience. On reflection I considered this to be best encapsulated within a more phenomenological perspective.

Hermeneutic Phenomenology is part of the broader theoretical stance known as 'Interpretivism'. Interpretivism comes from the philosophical belief that what distinguishes social actions from the biological, physical and chemical ones is that social actions are inherently meaningful (Crotty, 1998). It therefore follows that in order for a person to be able to understand the meaning of a social action, they must first be able to place the action in the context of the system of meaning in which it occurs (Schwandt, 2000). 'Phenomenology' and 'Hermeneutics' are broad theoretical perspectives within Interpretivism. While they share the core principle of 'meaningfulness', how this meaning or knowledge is seen to be generated varies between the two (Crotty, 1998; Schwandt, 2000).

Phenomenology is the study of the world as it is experienced before it is categorised or reflected on (Van Manen, 1997). From a phenomenological perspective the world or 'life-world' is not the same as the physical 'world'. It is the set of relationships, practices, rules and language with commonly understood and shared meanings that people acquire as a result of being part of a particular culture (Leonard, 1994). Phenomenologists argue that we depend on these shared meanings in order to function, but for the majority of the time the 'world' is so all-consuming that we are oblivious to its components, and they only appear to us in a conscious way when they are disrupted or analysed (Leonard, 1994).

Phenomenologists further argue that if people can put aside or bracket their own learnt understanding of a phenomenon and actively look at it, original or enhanced understandings of the meaning of everyday experiences will emerge (Husserl, 1970; Smith, 1998a). Phenomenology focuses on the very nature or 'essence' of an experience and aims to establish what differentiates and defines that experience as unique from others (Crotty, 1998; Laverty, 2008). It does this by systematically revealing and describing the internal meaning structures of 'lived' experience (Schwandt, 2000).

The hermeneutic perspective, also referred to as 'hermeneutic phenomenology', overlaps with the phenomenological approach in that it too looks at life-worlds and how meaning is

interpreted and constructed between individuals in the context of a shared culture. While hermeneutics is also interested in the 'essence' of a phenomenon, it places additional emphases on the importance of cultural 'texts', bringing in for consideration elements such as written communication, arts and music, in addition to verbal communication, to aid interpretation of meaning (Laverty, 2008). The fundamental difference between hermeneutic and phenomenological perspectives is that hermeneutics stipulates that it is not possible for a person to put aside their own understandings when looking at an experience; to describe something is to interpret it through a set of established biases (Schwandt, 2000). Researchers therefore need to be aware of their own preconceptions and cultural norms in order to account for these interpretive influences (Laverty, 2008).

From the hermeneutic perspective objectivity in relation to the meaning of a lived experience does not come from a decontextualized neutral position. Instead, skills, practices and meanings are objective in the sense of being shared and therefore verifiable, both within the researcher's own world and that of the research participants (Leonard, 1994). To achieve this level of 'objective' meaning, researchers use a process called the hermeneutic circle which moves between interpretations of the parts of a phenomenon under study and the whole (Chadderton, 1994).

The premise of the circle is that by systematically exploring the whole, new insights and an increased depth of understanding of the phenomenon will be produced. This information is then used to examine the sub-components of the phenomenon, in turn resulting in new understandings that need to be re-explored in terms of the whole (Leonard, 1994). This cyclic process has no clear termination point and is dependent on the researcher deciding when they have reached the point of 'optimal understanding'. Gadamer (2004) argued that while it is difficult to predict or justify the exact point at which optimal understanding has been achieved 'everyone knows it when it happens'. In order to follow a hermeneutic process the researcher must be self-reflective, while staying true to the data, honouring the lived experience of the participants without venerating it (Laverty, 2008).

In this research I maintain a hermeneutic phenomenological perspective. In order to achieve the research aims I will describe and interpret the 'life-world' of those involved in PPI. This will be achieved by mediating between the internal worlds of the participants and my own reflections on the meanings of these worlds. While these reflections were corroborated through working with others, I recognise that my own belief structures

impacted on the data collected and on my interpretations of that data. In order to clarify potential biases arising from my own experiences and establish transparency regarding my interpretations I needed to be continually reflexive and explicit about my positioning (Creswell, 2007).

2.3.1 My initial positioning

While it is impossible to be value free or to attain 'objectivity', by being reflexive and open about our own identity and its potential impact on the research, a level of distance can be established between the researcher and the data. This is seen as a key component of qualitative research (Green & Thorogood, 2004). My reflections on conducting this research are touched on briefly in latter parts of this chapter and addressed in the discussion. However, I have been aware since I first applied for this PhD that there was one component of my identity that I would have to be continually mindful of, as it had the potential to affect the research and it had contributed to my motivation for doing this PhD.

From the age of six I have been recognised as having the specific learning disorder, dyslexia. My parents' response to mine and my older sister's dyslexia was to become active members (Head and Secretary) of the local Dyslexia Association and have been referred to as 'Parents with Elbows'. They are strong believers in fighting for support and maintain that if people accept that they have no power in a situation, then they have none. This is an attitude that I have absorbed over the years and have repeatedly put into practice since I took responsibility for establishing my own learning support at university. Eighteen years of interacting with a collection of professionals in a rigid educational system has left me with the belief that while professionals hold a breadth of knowledge and collective experience that is invaluable, the individual with the condition has a substantial amount of information and experience which those who have not experienced the condition have no direct access to. I believe that combining the two sets of knowledge will result in better outcomes for the people involved than relying solely on only one perspective. Consequently while having no particular understanding of the best method(s) for implementing PPI, or the specific benefits and challenges, I started from a value position that people with epilepsy and their families should be involved in epilepsy research; and that, if done well, PPI can increase the quality of research and also have a positive impact on those involved.

Also influencing my beliefs and potentially balancing my experience of the 'patient' position is that fact that prior to starting this research I worked as a research assistant for four years

within a university. Adopting a similar ethos to that embraced by PPI, the research team of which I was a part felt that as the research was about university students, then university students should be involved in the research process as more than just participants. This aim was not always realised, despite most of the research team supporting it. This experience, I believe, gave me insight into the difficulties encountered by individuals whose role is to coordinate and implement research and a partial understanding of some of the systems and constraints they are working under.

2.4 Ethnography and multi-sited ethnography

Ethnographic methodologies derive from the principle that knowledge is constructed. Consequently these methodologies are in tune with my hermeneutic phenomenological underpinning (Van Manen, 1997). Ethnography is considered an appropriate design when research is aiming to: *“describe how cultural groups work and explore the beliefs, language, behaviours and issues such as power, resistance and dominance”* (Creswell, 2007, p. 70). They are also considered useful when developing an understanding of complex relationships from multiple perspectives (Kendall et al., 2009; Long, Hunter, & Van der Geest, 2008). Consequently an ethnographic approach addresses both my epistemological position and the research objectives, providing a vehicle for looking in-depth at the potentially disparate perspectives surrounding PPI.

Savage (2000) places the origins of ethnography within social anthropology, which traditionally explored small ‘non-western’ communities which were considered to have discrete, culturally specific, practices and beliefs. In the early 1920s ethnography helped anthropologists to facilitate a shift from reliance on secondary data sources to researchers having personal experience of the cultures that they investigated (Risjord, 2000). Sociology has always been closely linked to anthropology but traditionally focused on western, urban settings and mainly drew on quantitative methodologies (Falzon, 2009). Sociologists working at the University of Chicago (or the ‘Chicago School’ as it is known) from the 1920s to the 1950s developed an approach to studying western culture that overlapped with that being developed in anthropology (Hammersley & Atkinson, 2007). This advocated the importance of fieldwork and the use of empirical data to build theoretical models and developing ethnography as its core mythological approach (Falzon, 2009). British and French sociology and psychology, however, persisted in the positivist tradition, favouring quantitative, experimental and deductive methods (Gallo, 2009). This largely continued

until the socio-political movements of the 1960s (civil rights, gay rights and feminism- see Section 1.5.2) put pressure on the social sciences to address issues of representation, power and ethics. This resulted in a multidisciplinary movement promoting the use of qualitative approaches, particularly ethnography (Hammersley & Atkinson, 2007; Falzon, 2009). One reason that ethnography was 'imported' into so many different disciplines was because, fundamentally, ethnography is the study of culture, which is not just core to anthropology but many other disciplines as well (Flick, 2009a; Patton, 2002). Consequently ethnography is no longer purely the domain of anthropologists and the Chicago School, but has been adopted by a range of disciplines including but not limited to: sociology, psychology, applied educational research, organisational studies, human geography, programme evaluation, and business studies (Hammersley & Atkinson, 2007; Falzon, 2009; Patton, 2002).

Brewer (2000) and Hammersley (1992) emphasise that both across and within disciplines there are different 'schools' of thought surrounding ethnography. Across these schools there are consistencies and these are what I draw upon. The defining characteristic of traditional ethnography is participant observation, with the researcher participating in the daily lives and events being studied over an extended period of time (Hammersley & Atkinson, 2003). Other defining characteristics of ethnographic research include using multiple methods of data collection, placing emphasis on context, reflectivity and a focus on what people do, as well as what they say they do (Savage, 2000; Tedlock, 2000). One advantage of ethnography is that it draws on the strengths of each of the types of data collection utilised while in turn compensating for some of their weaknesses. For example, semi structured interviews used as a single strategy (see Section 2.6.2), which would have been the alternative methodology in this case, have the advantage that they supply in-depth information about participants' views and experiences. They allow participants the chance to expand their ideas and explain their views, while giving the researcher access to accounts about settings and events that they may not be able to observe themselves (Denscome, 2007; Hammersley, 2006). However, a disadvantage of this approach is that interview data is removed from the experiential context in which the experience took place and analysis can only be based on what participants 'said' or 'think' happened. By using interviews in conjunction with participant observation (see Section 2.6.1) it is possible to see the interlinking between different aspects of the culture under study: looking at the wider processes, relationships, connections and interdependency of the actors in the

setting rather than looking at one person's perspective in isolation. In addition, by spending an extended period of time with the participants during the observation process the researcher can establish rapport and trust with the participants, which in turn can facilitate honest, uninhibited discussion during the interviews. This allows for disclosure of information that might not be obtained during an interview where the interviewee has limited or no prior relationship with the researcher.

The ethnographic approach is underlined by the assumption that accessing beliefs and behaviours in the context in which they occur will aid understanding and provide a holistic perspective (Patton, 2002). Ethnographers therefore place importance on exploring the meanings of social interactions, as opposed to testing a hypothesis (Atkinson & Hammersley, 1998). It is not a case of having no aims, as this would result in voluminous and unfocused data that potentially does not address the original motivation for the research. Rather, ethnographic research has flexibility built within its aims (Agar, 1996; Fox, 2004; Hammersley & Atkinson, 2003). Instead of planning precisely what will be done at each stage, an ethnographic methodology responds to the research findings as they unfold and narrows its focus through on-going analysis (Lofland, 2002). While this flexibility allows for the research to develop in light of ongoing analysis it also holds the danger of methodological arbitrariness that is not always easily justifiable to those outside of the project (Flick, 2009b). In conjunction with this, like many qualitative research approaches, subjectivity is a potential methodological issue in ethnography, as the interpretation of the culture under study is variable, dependent upon the researcher's positioning and perceptions (see Sections 2.4 & 2.4.1) (Goodson & Vassar, 2011). The level of emphasis placed on context within an ethnography makes it problematic to generalise findings to other populations, because the information that is generated is based on cultural and even site-specific responses (Goodson & Vassar, 2011; Savage, 2000) in a way that would not hold as true with a purely interview based approach that used purposive sampling across multiple contexts. It also needs to be noted that ethnographies have a greater potential to invite ethical issues associated with invasion of privacy and informed consent (Denscome, 2007). I discuss how I have approached issues of generalizability and consent in Sections 2.7.4 and 2.9 respectively.

One of the main criticisms of traditional ethnography at a more theoretical level is that it depicts the people it studies as being in a void, uninfluenced by time and broader social constructs (Agar, 1996). In modern ethnography research sites or cultural settings, often

referred to as 'fields', are no longer considered to be discrete entities or stuck constructs; rather they are seen as overlapping and time dependent, with some fields only existing for a finite amount of time (Hammersley & Atkinson, 2003; Hannerz, 2003; Marcus, 1998). This is likely to apply within the epilepsy research community, as research groups form and disperse as research projects are identified, developed, funded and end. Moreover, members often belong to more than one group, with many members of the broader epilepsy community knowing or knowing of each other³. Therefore, it would be superficial to carve out one 'site' or 'field' within this area. Multi-sited ethnography (MSE) developed to accommodate this conceptual broadening of the field and was first seen in migration studies where both the points of departure and arrival were studied (Watson, 1977).

MSE is translocal, as the object being studied cannot be confined to one place (Hannerz, 2003). Marcus, (1998) one of the pioneers of MSE states that: "*Strategies for quite literally following connections, associations and relationships are thus at the very heart of designing multi-sited ethnographic research*" (p. 81). The 'object' being followed can consist of the people, an artefact, a metaphor, a story, a biography or a conflict (Marcus, 1998). It is this conceptual link that differentiates MSE from comparative studies (Hannerz, 2003). This broadening of the 'field' has been reflected in a number of health related ethnographies. Traditionally such ethnographies focused on one location such as a hospital ward (Coser, 1962) or clinic (Good, Herrera, Good, & Cooper, 1985; Cowie & Roebuck, 1975) rather than taking a more conceptual perspective. However, later studies adopted a broader conceptual perspective. For example, Martin's (1994) MSE on the role of immunity in American culture viewed the immune system and the 'field' rather than looking within one 'site'. For Martin, the immune system could only be understood by looking at it through the perspective of actors who were differentially positioned in relation to the problem and from different settings. These included volunteering as a 'buddy' at a centre for HIV sufferers, observations in an immunology lab and analysing public representations of the immune system in advertisements. Cooper (2012) used MSE to explore organ donation in black and ethnic minority communities. Rather than focusing on a single site, data were collected across two acute hospital Trusts and in the wider 'community' such as religious temples. Narrative and observational methods were used to understand the experiences of intensive care staff, donation nurses, religious leaders and minority ethnic transplant recipients. The importance of exploring all facets of the organ donation process was seen as

³ This was evident during data collection.

key, as it was concluded that low minority donation rates are not a result of a discrete temporally- bound decision making process but rather a result of a set of situated processes that draw on the experience, preconceptions and cultures of all involved (Cooper, 2012; Kierans & Cooper, 2013).

When compared to traditional ethnography, MSE is seen as providing a wider breath of knowledge but less depth (Hammersley & Atkinson, 2003). MSE does not aim to give a complete account of the world as this would be unachievable, but rather to provide enough of an insight to be useful (Marcus, 1998). Due to logistics and time constraints it is not possible to dedicate the same amount of time to many sites as it would be to a single one. However, as Hannerz (2003) notes in many of the new fields of study people are often physically and socially confined (e.g. sitting at a computer or on their own in an office) and it would not be beneficial or practical to spend a substantial amount of time observing them in such contexts. This, combined with the multisitedness, means the MSE is based more on interviews and less on observation than traditional ethnography (Hannerz, 2003). The resultant decrease in field time can create a conflict with the requirement of ethnographers to develop an 'intimate' understanding of the phenomenon. Hammersley (2006) suggests that these changes in the nature of ethnography have led to an increased chance that the data collected is 'ahistorical', failing to take into account the wider local and historical perspectives; and with the ethnographers sometimes treating people as if their behaviour is entirely a product of the situation being observed rather than who they are and what they do elsewhere, because the ethnographers do not have observational data relating to the rest of the lives of those they study.

In order to still achieve depth, as well as breadth of knowledge the number and types of sites needs to be given careful consideration at the design stage. Accordingly, MSE consists of a selection of sites from all possible sites that could be included. In tune with the unfolding nature of the method, sites may not be predetermined but rather be chosen gradually as the story develops, insights are gained, and to some extent by chance (Hannerz, 2003). This method of site selection can be a problematic aspect of MSE, as there is a chance that optimal data might not be obtained (Lofland, 2002).

2.4.1 Assessing the quality of ethnographic research

Unlike quantitative research, it is not possible or necessarily desirable in qualitative research to attempt to pursue or measure reliability, objectivity and validity as conventionally defined (Bailey, 1997). Nevertheless the need to establish what is 'trustworthy' data and what constitutes a 'plausible' interpretation of the data remains (Lather, 1991; Wilcott, 1990). Whitemore, Chase and Mandle (2001) synthesised key validity criteria within the literature and concluded that there are four primary criteria by which qualitative research should be judged. These are credibility (how believable the findings are), authenticity (if the subtle differences in the voices of all participants are explored), criticality (evidence of critical appraisal of the data) and integrity (repetitive checks of validity and unpretentious presentation of findings). In line with these generic criteria for assessing qualitative research, Hammersley (1990) offers a composite list of evaluation criteria that are specific to ethnographic research, four of which are considered key validity measures for an ethnography (Savage, 2000, p.1401):

1. The extent to which the influence of the research design and strategy on findings is considered (the reflexivity of the account), and the existence of an audit trail
2. The extent to which findings have relevance to those in similar settings
3. The credibility of the account to readers and those studied
4. The consistency of claims compared with empirical observations and data

Silverman (2006) stipulated that the most logical way of meeting these criteria is a combination of 'triangulation' and respondent validation. Triangulation involves collecting multiple and divergent data sources to corroborate findings, testing one source of information against another to prove or discount a theory (Fetterman, 2009). Creswell (2007) advocates the use of prolonged participant observation as one of the forms of data collection to provide opportunities for respondent validation/checking. Observation and triangulation of data in this research was integral as part of the MSE approach (Fetterman, 2009) (see Section 2.6). Respondent validation or 'member checking' involves obtaining participants' views on the accuracy of the findings, to corroborate how 'truthful' the findings are. Respondent validation in my research was iterative and extensive. The time frame and method of the research allowed me to clarify points that were raised in early interviews in latter ones and to directly ask questions about things that I had observed to test my interpretations. The number of informal interactions I had with participants allowed me to explain my current theories to them and get their feedback. Developing findings were periodically presented at a range of events that allowed me to get feedback from professionals who, while not directly involved in my sites, had extensive PPI

experience. In addition, as explained in more depth in 2.6.2 my primary supervisor was also a participant in one of my sites; consequently she was present at a number of my observations and could compare and contrast her interpretation of events with my own.

A factor that is key in determining the quality of qualitative research but is often not explicitly stated is the competence of the researcher (Guba & Lincoln, 1998). Through my undergraduate and master's studies I developed a basic understanding of qualitative research methods. I was able to put this knowledge into practice during my four year role as a research assistant, conducting semi-structured interviews, focus groups and data analysis. To further develop my practical skills, I undertook two courses in Neuro-Linguistic Programming, which enhanced my methods of communication, giving me a greater insight into verbal and non-verbal language, observation skills and rapport building. As mentioned in Section 2.3 as part of my PhD training, I undertook an advanced qualitative research methods course that focused on theoretical and methodological aspects of such research. This present research required all of my theoretical and practical knowledge. Working with a new population in an unfamiliar setting required me to apply and develop my skills. I also had to learn more about conducting observations and writing fieldnotes as this was not something I had previously done in a formal capacity. In order to ensure the research was of sufficient quality, my supervisors looked in depth at my early interviews and we had regular ongoing discussions regarding data collection and content.

A common methodological problem within ethnographies is the tendency to defer to, or side with those in the subordinate group (Becker, 1966). In the present case this could result in me being more sympathetic to the representatives' perspectives rather than giving a balanced analysis. Liebling (2001) maintains that it is possible to appreciate competing perspectives and give equal consideration to all sides. I aimed to achieve this neutrality in part through the respondent validation process and my own reflectivity, particularly with reference to drawing on my experience of both the patient and researcher roles.

2.5 Why epilepsy and epilepsy research?

When choosing the context for my research it quickly became apparent that I needed to establish clear parameters for investigation. My view is that it would be possible to conceptually link most occurrences of PPI in health research, this would create an unmanageable number of possible research sites. An efficacious way of establishing

selection criteria was to identify a single health condition to focus on and a story⁴ that had closely related, clearly defined sites. The aim would then be to address both the context specific nature of PPI and facilitate the comparison of different approaches (research Objective 4). I will now explain why I chose to focus on epilepsy research and how I developed my knowledge of this area.

In 2006 The UK National Institute for Health Research (NIHR) established a Comprehensive Clinical Research Network (CCRN) to support and coordinate clinical research and to facilitate the conduct of clinical trials and other high quality studies (UKCRN, 2010). Consisting of six topic-specific Clinical Research Networks and a Primary Care Research Network, the CCRN's aim was to establish national research priorities and support a national portfolio of clinical trials and other studies (Ng & Weindling, 2009). Within these networks PPI was prioritised from the beginning, with designated funding attached to a PPI 'lead' role, with the remit of facilitating PPI in the network. The drive to integrate PPI within the networks was: *"based on the premise that involvement is ethical, enhances research, demonstrates the openness of research, improves recruitment, and enriches the process"* (Stewart, 2010, p.5).

The focus of the six topic-specific networks reflected the Department of Health (DH) priorities at the time they were established (Cancer, Dementia and Neurodegenerative Diseases, Diabetes, Medicines for Children, Mental Health and Stroke). For this reason some clinical topics were not represented by their own topic-specific networks, falling instead within the remit of one of the six CCRNs. For example Parkinson's disease, Motor neurone disease and Huntington's disease are part of the Dementia and Neurodegenerative Diseases portfolio. However, epileptologists⁵ across the UK considered it important that an epilepsy-specific research network was created, in order to ensure the quality of epilepsy research and drive forward an evidence-based research agenda. As a result of this researcher-led initiative, funding was obtained from various UK epilepsy charities and the UK Epilepsy Research Network (UKERN) was launched in February 2010.

⁴ The word 'story' is being used for its MSE connotations. The 'story' includes the tracking of processes, narratives and associations within a specific context (Marcus, 1998).

⁵ Neurologists who specialize in the treatment of epilepsy are 'Epileptologists', but when used less formally within the epilepsy community this term is also refers to researchers and other health practitioners with the same focus.

In 2008 the Medical Research Council, in partnership with the NIHR, established eight research 'Hubs' for Trial Methodology Research. In line with the CCRNs the hubs were created as a resource to improve the design, conduct, analysis, interpretation, and dissemination of clinical trials, particularly in methodologically challenging areas (MRC, 2010). The North West Hub for Trials Methodology Research (NWHTMR), which funded my PhD, is a collaboration of three Universities: Liverpool, Lancaster and Bangor. It has a focus on three methodological research themes (early phase trial design and analysis, later phase trial design and analysis, and patient perspectives), with the aim of developing and translating methods for application across key clinical areas including Drug Safety, Medicines for Children, Cancer and Epilepsy. The inclusion of epilepsy as a key clinical area within the NWHTMR reflected the large numbers of epilepsy-focussed researchers and clinicians working within Liverpool, some of whom work as part of the Hub and in turn were involved in the development of the UKERN.

Like the NIHR-funded networks, members of the UKERN placed great importance on PPI and were starting to develop their own PPI strategy about the same time that this research was being conceptualised. This offered a unique opportunity to follow the process of PPI implementation within a research network from its inception, exploring how decisions about PPI were made and the consequences of these decisions. Further exploration into the UKERN as a potential 'story' identified a range of other benefits. The UKERN research portfolio could provide a range of potential research sites, covering different aspects of the PPI process, which were not just conceptually linked but belonged to the same story. This could facilitate my aim to compare different types of methods or approaches to PPI within a similar context. Epilepsy research generally consists of clinical drug trials (see Section 2.5.1) which links with the remit of the Hub and the original funding for my PhD. In addition, my focused literature review revealed little or no research exploring PPI in epilepsy or research networks. Therefore, the UKERN was chosen as the main site from which the other sites were identified.

I followed the development of the UKERN from its launch for 25 months (see Figure 6 for detailed timeline). From the outset four sub-groups consisting of a management group, and three Clinical Study Groups (CSGs) were established. Each of the CSGs had a remit to focus on a different aspect of epilepsy research: Diagnosis and Aetiology, Interventions and Therapies, and Impact and Outcomes. Each group had between 10 and 20 members consisting of two representatives, clinical and non-clinical researchers. The CSGs initially

agreed to meet approximately every three months through a teleconferencing service and annually face-to-face at the annual conference of the UK branch of the International League Against Epilepsy (ILAE). Later, an additional yearly face-to-face meeting was included. Through consultations with one of the main epilepsy charities it was decided that representatives would be selected through a formal application and interview process. The six selected representatives then attended a research methods training day run by members of the network before becoming active members of the CSGs.

2.5.1 Developing my understanding of epilepsy research

In order to understand the UKERN I needed to develop my understanding of epilepsy and epilepsy research. Initially my knowledge was limited to 'common' knowledge, that of a general member of the public. For instance, I knew people with epilepsy have seizures that can be difficult to control, that this may affect their ability to drive and that seizures can be brought on by flashing lights and images. When first going into the field I was unsure what level of epilepsy knowledge I required. This uncertainty originated from the fact that epilepsy was not the focus of my research and that naivety about a setting, commonly known within the literature as taking the role of a 'stranger', can be considered advantageous in ethnographic research (Schuetz, 1944). It is argued that identifying discrepancies between the taken-for-granted knowledge in the field and your own preconceptions and cultural norms throws pertinent information into relief, thereby aiding analysis (Agar, 1996). Also, in line with my method and methodology, facts about epilepsy are not as important as what the people involved believe to be true (Crotty, 1998).

During my observations I paid particular attention to epilepsy related information that both the professionals and representatives took for granted. I recorded and researched terms identified during data collection whose meaning I did not know. I based my initial broader reading on the recommendations of my informants. These included reading two books written as guides for people with epilepsy, 'Epilepsy The Facts' (Hopkins, 1984) and 'Living With Epilepsy' (Chadwick & Usiskin, 1987) and looking at the leaflets produced by the UK epilepsy charity, Epilepsy Action (EA). These leaflets cover the most pertinent issues and are often the first point of call for people wishing to learn more about their epilepsy (EA, 2012b). In addition I found Joanne Taylor's (2010) PhD thesis on 'The natural history of cognitive functioning in people with newly diagnosed epilepsy' particularly useful, as it outlines the aetiology, diagnosis, treatment and progression of epilepsy. In order to place

my findings within the epilepsy context, I will now summarise some of the key aspects of epilepsy and epilepsy research that I discovered over the course of my data collection.

The International League Against Epilepsy (ILAE) an international forum for debate about key issues in epilepsy, currently uses the following definition of epilepsy:

“An epileptic seizure is a transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain. Epilepsy is a disorder of the brain characterised by an enduring predisposition to generate epileptic seizures and by the neurobiological, cognitive, psychological, and social consequences of the condition. The definition of epilepsy requires the occurrence of at least one epileptic seizure.” (Fisher et al., 2005, p.470)

The importance of this definition of epilepsy is that it reflects that having epileptic seizures can have far reaching consequences in a person’s life that may be more debilitating than the seizures themselves (Taylor, 2010). For example:

“The physical hazards of epilepsy resulting from the unpredictability of seizures; the social exclusion as a result of negative attitudes of others toward people with epilepsy; and the stigma, as children with epilepsy may be banned from school, adults may be barred from marriage, and employment is often denied, even when seizures would not render the work unsuitable or unsafe. Furthermore, epilepsy is a disorder associated with significant psychological consequences, with increased levels of anxiety, depression, and poor self-esteem compared with people without this condition.” (de Boer, Mula, & Sander, 2008, p.540)

Epilepsy and epileptic seizures are not homogeneous, with these terms encompassing a range of approximately 50 neurological conditions with differing courses, neurological effects and prognosis as reflected in the complex classification system (Engel, 2001; Joint Epilepsy Council of the UK & Ireland, 2012). At the most basic level, seizures are classified as focal (partial) or general. Focal seizures originate in one part of the brain, general seizures involve epileptic activity in both hemispheres. Seizures are then further categorised by the specific areas of the brain affected and how the activity spreads over the course of the seizure (EA, 2012a). The development of chronic epilepsy in childhood is likely to be a result of congenital, genetic and developmental conditions. Head trauma, tumours and infections may result in epilepsy at any time (de Boer, Mula, & Sander, 2008). Risk factors for epileptic seizures include metabolic disturbances, stress, sleep deprivation, fatigue, alcohol, exercise, the menstrual cycle, toxins and drugs (Taylor, 2010). During my research both professionals and representatives repeatedly highlighted the complexity of epilepsy, stressing the point by providing examples such as a teenage boy with epilepsy having very different concerns and priorities from those of a pregnant women; also, that

those who have seizures regularly may have a very different experience to those who have them sporadically.

In terms of the prevalence of epilepsy, it is generally agreed that five percent of a given population will experience at least one epileptic seizure in their lifetime and one third of these will then be diagnosed with epilepsy (Sander, 2003). Currently there are approximately 500,000 people with epilepsy in the UK (Joint Epilepsy Council of the UK & Ireland, 2012). Although epilepsy can be diagnosed at any age it occurs more frequently in those under 20 or over 60 (de Boer, Mula, & Sander, 2008). People with epilepsy have a standardised mortality rate two to three times higher than the general population (Sander, 2003). It has been estimated that symptomatic epilepsy may reduce life expectancy by up to 18 years (Gaitatzis, Trimble, & Sander, 2004). However, the majority of people with epilepsy will achieve seizure freedom following treatment with antiepileptic medication. Cockerell et al (1995) found that after nine years, 68% of patients with epilepsy had achieved a remission of five years and 86% had achieved a remission of three years.

Reynolds and Trimble's (2009) article on the history of epilepsy reflects that throughout most of its recorded history, epilepsy has been viewed as a supernatural or a mental disorder, linked to possession and insanity. Even in the second half of the 19th century, when neurology developed as a discipline giving new understanding to conditions such as stroke and Parkinson's disease, epilepsy was still considered a mental disorder. This was because epilepsy was not found to be linked with brain lesions and the psychiatrists treating those with epilepsy associated their symptoms with mental or behavioural disorders (Reynolds & Trimble, 2009). It was not until 1960 that the World Health Organisation categorised epilepsy as a neurological condition rather than a mental disorder (Reynolds & Trimble, 2009). This history, combined with the stigma associated with disability and mental illness, has become a deep rooted part of the epilepsy community's psyche.

As the understanding of epilepsy has developed, so have nonmedical support systems in the UK. In line with the evolution of PPI in health research and the development of public activism (see Section 1.5.2) the epilepsy community as a whole is increasingly more politically shrewd, using their national infrastructure of charities and groups to influence both policy and research (Lee, 2000). As such they are no longer a passive patient group, a trait reflected in their representatives.

Since the recognition of epilepsy as a neurological disorder there has been a proliferation in the development and use of AEDs (AED was the first acronym that I witnessed used as 'common knowledge'; after looking it up I found it stands for Anti-Epileptic Drug). AEDs are now the primary treatment strategy for epilepsy (Taylor, 2010). Reflecting this, a substantial amount of epilepsy research involves clinical trials, aimed at developing or comparing AEDs and is a key area of interest for representatives. There is also a significant amount of research looking into possible genetic causes of epilepsy. Consequently alongside the vocabulary and knowledge linked to research methods, representatives must also contend with the chemical and biological terms used. The extent to which representatives need to understand this knowledge is a point of contention raised in the results chapters.

2.6 Data collection methods

In line with the ethnographic methodology I used multiple methods of data collection, with the majority of my data coming from interviews and observations. The number of observations and interviews I conducted at each site were context specific but the approaches I used were largely consistent across the sites. In this section I explain the data collection methods I used in relation to the UKERN site. In Section 2.7 I outline how I implemented these same approaches within the other sites.

2.6.1 Observations

As previously discussed, observation is one of the cornerstones of ethnographic data collection. The main goal of observational data is to describe (Patton, 2002). Observation requires the systematic noticing and recording of events and behaviours, focusing on what is done, as well as what is said is done (Marshall & Rossman, 1995). One benefit of this type of data collection is that it provides opportunities for the researcher to catalogue routine occurrences that may be key to a culture but are so ingrained that they are not apparent to its members and as such may not be mentioned in an interview (Patton, 2002).

While conducting observations the researcher places themselves on a continuum between participant and complete observer (Marshall & Rossman, 1995). For this research I was overtly present to observe PPI in the network and all members were aware of the reason for my presence. However, I did not just observe, I also interacted with the network members and participated as required. Vinten (1994) categorised this type of observation

as explicit observation. The main advantage of this type of observation is that it offers flexibility within the role without engendering the ethical problems associated with some observational approaches. It also allowed me to have direct communication with participants, reducing the likelihood of imposing my own preconceptions on what I was observing, while maintaining some degree of separation (Flick, 2009a). Schatzman and Strauss (1973) also raised the point that 'pure' observation without interaction can leave participants unsettled and wondering what the researcher is 'really up to', thus impacting negatively on participants' state of mind.

The disadvantage of this type of explicit observation is that the more I interacted with the field the more I potentially affected it. I tried to keep my impact to a minimum by saying as little as possible in the meetings I observed, only talking when called upon. However, as Atkinson (1976) acknowledges reciprocity is key to any relationship, and if a researcher is always 'taking' from the participants and never 'giving' discontent can occur in field relations. He suggested that this can be avoided by the researcher occasionally 'helping out'. With these two contradicting motivators in mind, I tried to periodically help out in ways that would have minimal impact. For example, on a few occasions the network coordinator could not be at a meeting and I would produce the minutes from my audio recording. Occasionally, I would transfer practical information across groups, for example, confirming whether another group had completed a task. This kind of knowledge transfer seemed benign, but I had to be very careful with my responses, if asked questions about others' opinions, to avoid breaking confidentiality (see Section 2.9.2).

Due to my presence from the start of the network and at all of the different CSG meetings, I am confident to say I was seen as part of the network. This had two main benefits, firstly it helped to limit the observer effect, as members of the group accepted me as one of them and as such were less likely to alter their behaviour. Indeed, they seemed remarkably happy to talk to me when they had time or something to say and ignore me when otherwise occupied. Secondly, when combined with the extended data collection time, it helped me to build rapport with the participants, allowing me access to more honest and holistic accounts and compensate for the odd faux pas I made. Although it must be acknowledged that my presence gave the implicit knowledge to both the representatives and the professionals that PPI was something to be aware of, which might not otherwise have been the case for all group members.

I originally focussed on 'descriptive observation', presuming that I knew nothing and trying to pay attention to everything (Angrosino & de Perez, 2000). After the first set of CSG meetings that included the representatives, I felt that I was starting to get a understanding of what was and was not pertinent to my study aims, so I shifted to a more 'focused observation'. As the name suggests, I used a more selective approach as to what I focused my attention on and recorded. The advantage of this was that I could obtain more information about the things I was focusing on, such as interactions between representatives and the 'professionals'. As with most focused observations the criticism of this method is that a third party might find it difficult to evaluate the choice of criteria used to determine what is and what is not attended to, as it is not always possible to articulate the reasoning for judgment calls made in a given situation (Vinten, 1994).

The nature of the network meant that I could observe the majority of the CSG meetings, since they rarely took place at the same time. On the three occasions they did, I alternated which group I attended and obtained copies of the meeting minutes from the others. I also observed the recruitment process (including discussions pre-recruitment and the interviews) for the representatives and a number of network events. Caron-Flinterman, Broerse and Bunders (2005) note that due to the implicit privacy agreements in the rules of most committees, members often do not feel comfortable giving details to outsiders about the decision-making process. My observer position meant I had access to information that would not necessarily have been revealed through interviews alone.

As noted earlier many of the CSG meetings were conducted via teleconference. I was able to audio-record these conversations, allowing for verifiable and accurate fieldnotes to be taken (with transcriptions of pertinent sections), but many of the criteria defined in the guidelines for writing ethnographic fieldnotes were not applicable as there were no visual cues. My fieldnotes that accompanied all observations and interviews were based on the recommendations made by Emerson, Fretz and Shaw, (1995) in their book, 'Writing Ethnographic Fieldnotes'. They emphasise the importance of indigenous meanings, interactional detail, being aware of your audience and documenting emergent thoughts and processes. It took me a few attempts to develop my own style of fieldnotes and there are situations where, in hindsight, I had not judged the level of detail correctly. I also learnt when and where it was appropriate to write my notes. It was often entirely acceptable to write notes during the formal meetings as others were also writing. Outside of the meetings I jotted down some cues and prompts for later elaboration. Or, if I felt that

something was particularly important and needed more intensive notes, for example, the wording of a conversation, I would sequester myself in the ladies' toilets to write so as not to draw attention to myself. This is a trick regularly reported by ethnographers, though it must be used sparingly to prevent missing activities or your participants thinking you have bladder problems! At the nearest opportunity, normally on the train home, all my notes were expanded in as much detail as possible and typed up. Gibbs (2008) noted that fieldnotes are often loose, unruly and messy. I found this to hold true with regards to my own notes. All my notes were revisited a day or two after the observation to ensure maximum information was recorded. I also made sure that my initial thoughts and more reflective thoughts were distinguishable within my notes.

The initial time frame for observing the UKERN was set at two years to fit in with the timeline of a PhD. However as noted ethnographic methods are flexible and adapt to meet circumstances. Towards the end of my designated data collection period the decision was made to delay the final representative interviews and include an additional three months of observations. The reason for this extension was to allow for the inclusion of a period of increased activity within the network and the observation of a 'catch-up and feedback' telephone conference between the representatives and the Network Director.

2.6.2 Interviews

In the course of conducting my observations I undertook a number of informal ethnographic interviews. Some researchers consider informal interviewing and participant observation as separate entities. They are however, arguably part of the same thing, with a large quantity of ethnographic, observation data coming from informal interviews (Fontana & Frey, 2005; Lofland, 2002). Informal interviews are essentially conversations but with an information gathering focus. Patton (1994) argued that people may be inclined to tell you more in a natural setting than in a formal interview setting, especially with regard to sensitive or emotive topics. I found that the information obtained in uncensored moments during casual conversations to be particularly revealing and useful.

In addition to the informal interviews, I conducted more formal, semi-structured interviews with selected participants. All individuals approached agreed to be formally interviewed in addition to being observed. This included the six representatives, the three CSG leads, the Network Director, the Network Coordinator and two advisers from an epilepsy charity. The formal interviews were done at key time points, with the representatives, Network Director

and CSG leads taking part in multiple interviews (see Table 3). The advisers from the epilepsy charity were interviewed first, after the launch of the network but before the representatives were recruited. The representatives and Network Director were approached to be interviewed just after the interview process but prior to representatives attending their first meeting (time point one), after one year (time point two) and at the end of data collection (time point three). The CSG leads were approached to be interviewed at time point one and three. Not all of the representatives or professionals were available at all time points. Table 3 gives a detailed accounting of the number of interviews by participant and time point. On average interviews lasted for around 50 minutes, ranging in duration from 20 minutes to 75 minutes (see Appendix 2 for example interview extracts).

A key professional informant for this site that is not adequately accounted for in the prior description is my primary PhD supervisor Professor Ann Jacoby. Ann was involved in the development of the network, recruiting and training the representatives and was an active member of a CSG group. As such she was an invaluable source of information about aspects of the network that I had no direct access to. Her reflections about events worked as a comparison point for my own observations, and her opinions obtained through informal interviews are common place among my fieldnotes. She is the one informant that was not given a pseudonym as our relationship needed to be explained for transparency (Ann gave consent for her lack of anonymity).

Due to time and resources constraints I decided not to formally interview the professionals in the CSG groups other than the leads. Instead I obtained their opinions through the other data collection methods. The semi-structured approach I used in my more formal interviews allowed me to have some consistency across the interviews while providing flexibility about what was discussed. The original topic guides (see Appendix 3) were developed to address the research aims. They were adapted and refined over the duration of data collection, taking into account the findings of my data analysis, the context and the timing of the interviews. To make the interviews as convenient and comfortable as possible for the participants they were offered a choice of face-to-face or telephone interviews. If they were face-to-face they took place at a location chosen by the interviewee, e.g. their home, place of work or in a café. Telephone interviews required me to adapt my interviewing style to compensate for a lack of visual clues, with more verbal communication on my part to maintain rapport.

In addition to the observations and interviews, 55 documents including the completed application forms, feedback forms from the training day and minutes from CSG meetings were collected.

Table 3: UKERN, participant information

Site	Pseudonym	Role	Basic biography ⁶
UKERN	Alex	Professional	Network Director, clinical researcher (Interviews at all-time points)
	David	Professional	CSG lead, clinical researcher (Interviewed at time points 1 & 3)
	Francis	Professional	CSG lead, clinical researcher (Interviewed at time points 1 & 3)
	Lee	Professional	CSG lead, clinical researcher (Interviewed at time point 2)
	Lucy	Professional	Epilepsy charity representative (Interviewed prior to representative recruitment)
	Emma	Professional	Epilepsy charity representative (Interviewed prior to representative recruitment)
	Angela	Professional	Network coordinator (Interviewed at time point 2)
	Ann	Professional	CSG member, facilitated recruitment and training of representatives, Professor, non-clinical researcher
	Faye	Representative	Epilepsy since she was 29 following a stroke, health professional, a representative for an epilepsy charity, 40 yrs. old (Interviewed at all 3 time points)
	Hazel	Representative	First fit aged 20, following birth of her daughter, largely controlled but when changing drugs had periods of uncontrolled epilepsy, worked for the government, masters in social work, a representative for an epilepsy charity, daughter has epilepsy, 66 yrs. old (Interviewed time point 1 & 2)
	Katie	Representative	Retired school teacher, epilepsy for 15 years, also had breast cancer, approx. 65 yrs, old (Interviewed at all 3 time points)
	Rick	Representative	Clinical practitioner working with people with epilepsy, teenage daughter has had uncontrolled epilepsy since the removal of a brain tumour when she was approx.12 weeks old, epilepsy charity volunteer, 51 yrs. old (Interviewed at time point 2)
	Ron	Representative	Health professional, had epilepsy since he was 15, daughter also has epilepsy, both controlled, 56 yrs. old (Interviewed at all 3 time points)
Rose	Representative	Health professional, brother has had severe epilepsy since he was 8 (36 years in total), 41 yrs. old (Interviewed at time points 1 & 3)	

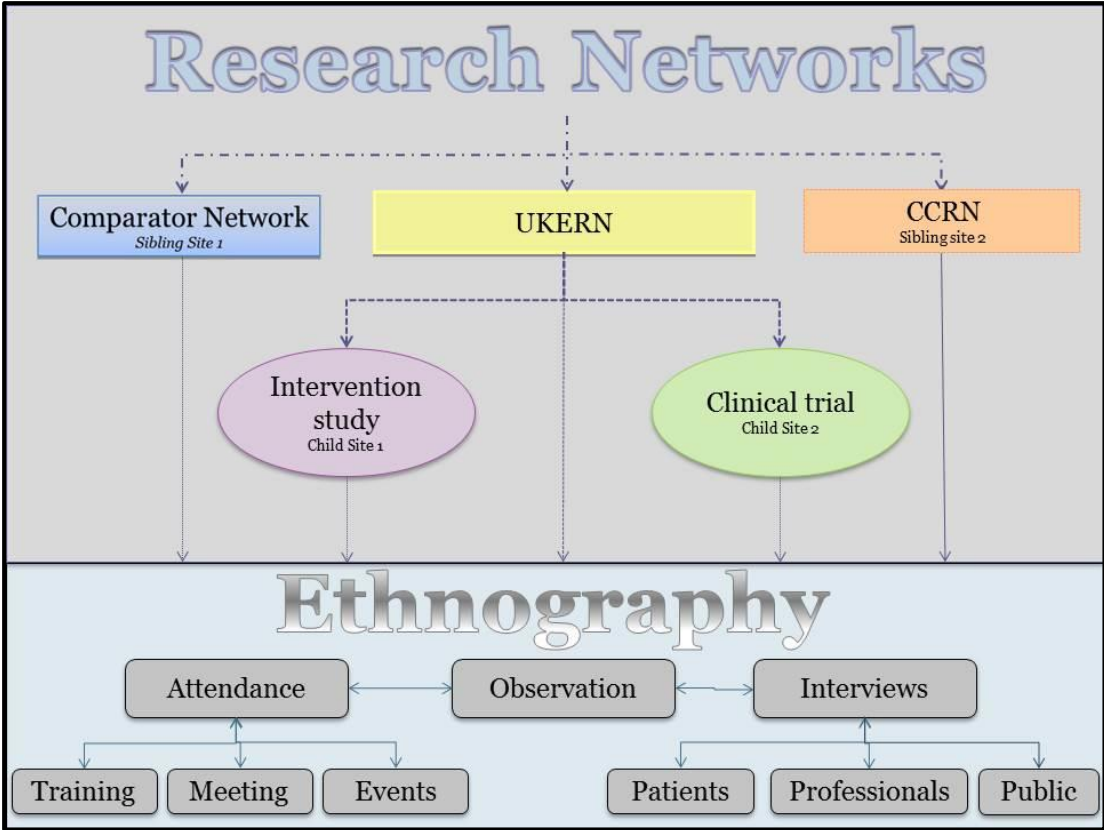
⁶ The information provided about each participant in this and subsequent participant information tables varies as a result of the amount of information known about each participant and the need to maintain anonymity. Approximate ages are given when actual age is unknown but enough other information was provided to make an informed guess.

2.7 Further site selection

Once the UKERN had been selected as the main site and context for this research, as justified in the preceding sections, decisions needed to be made regarding the selection of the other sites. Clinical trials are a key part of the activity of all the UK research networks and a central component of epilepsy research. It was hoped, therefore, that as the network developed, it would be possible to observe how PPI was implemented within a number of trials supported by it. Within the time frame of my research it would not be possible to follow a single clinical trial from the funding application stage through to dissemination of findings, as most trials take significantly longer than the period of time my studies allowed for. Additionally, given the multiple possible PPI approaches, I considered it advantageous to look at the different PPI approaches adopted at both the network and the clinical trial level. The UKERN was in its infancy, so had a limited trial portfolio. The Network Director identified three clinical trials (the only ones formally attributed to the network at that time) that I could potentially follow, all three of which were at the design and funding stage. While this was not ideal, as I had hoped to look at PPI across all stages of the research process, it did provide an opportunity to look at different approaches to PPI at the design stage of multiple trials within the same disease context. Arguably this is the time point where PPI may have the most impact on the design and implementation of a project. With the Network Director and my primary supervisor acting as gate keepers, I was able to gain access to all three trials with ease (see Appendix 4 for a copy of approach letter). In fact, the lead investigators all seemed genuinely interested in my research. Two of the clinical trials had already been submitted for funding at the start of the data collection period. While they were both subsequently funded, one did not become active until after the data collection period for my own research had ended and so could not be included as a site. The third trial was at the design stage when I started my studies and, at the time of writing, funding has yet to be secured. However, PPI was central to the process the group designing the trial went through to develop the bid and related projects. Consequently this trial made for an interesting site. In order to demonstrate the relationships between the different research sites, they are described as they would appear in a hierarchical tree structure (see Figure 5). The trials are 'child' sites stemming from the 'parent' UKERN, whereas the sibling sites are not dependent on the UKERN, but come from the same 'grandparent', the research network concept. This section gives a brief description of each site and details of

participant selection. Chapter 3 describes each site in more depth, exploring the PPI process each site undertook.

Figure 5: Research design



2.7.1 Child site one: intervention study

In order to maintain confidentiality it is not possible to give information that might identify any of the sites; so the following information has been anonymised as much as possible while still aiming to provide enough context to understand the data analysis⁷.

The research team at child site one (CS1) were working toward submitting a grant application for a specific epileptic condition. They were active in ensuring that they had PPI in both the development of the funding bid and the proposed psychoeducational intervention to be studied within the research if funded. The approach they took was a consultative one; they obtained funding to run a research user group (their terminology) four times over a six month period prior to the main funding bid submission, with a view to keeping the group going if the project was funded. The group consisted of eight

⁷ It is not possible to anonymise the UKERN and the lack of anonymity has been agreed by the Network Director.

representatives, four of whom attended most meetings, two who attended sporadically, and two who joined the group late (during my second observation). The group was organised and facilitated by the project research assistant (Rachel) with the lead researcher (Nick) in attendance part of the time.

The group followed a prescribed agenda set by Rachel and Nick, for example commenting on the proposed intervention, the patient information sheets and the departmental website. At the start of data collection the group had already met twice, consequently I observed two meetings (in addition to taking fieldnotes I was given permission to audio record these meetings, which I later transcribed) obtaining copies of the minutes and documents from the previous two and a later meeting that I could not attend. In addition to these documents the research team generously allowed me access to the research bid and intervention documentation.

Rachel and Nick were the professionals I interviewed at this site. Although there was a larger group of professionals involved in developing the bid itself, they were not actively part of the PPI process and as such were not approached. Following Rachel's advice I contacted the six representatives who were present during my observations of the user research group via email. Five responded to say they were happy to be interviewed. I was then able to secure interviews with three of them. The three representatives I interviewed from this site were the only representatives who were present at all of the user group meetings (see Table 4); this was advantageous because they were the most knowledgeable representatives about the PPI in the site. However, had it been possible, I realise it would have been interesting to see if there were any differences between the core and sporadic representatives with regards to their motivations for involvement. All interviewees chose to be interviewed in person and on average interviews took 45-50 minutes.

2.7.2 Child site two: clinical trial

Child site two was a UK-wide randomised controlled trial focused on the clinical management of pregnant women with epilepsy. The study was awarded funding and commenced in spring 2011. The approach the research team used for PPI is difficult to label as the researchers did not define it as such. This made for an interesting site as they did not deliberately set out to incorporate PPI into the research process (see Chapter 3). Rather, the researchers stated that they conducted a feasibility study where patients were asked to comment on the relevance of the proposed study, prior to compiling the funding bid. They

had also appointed a patient representative to the data monitoring committee and steering group. Data collection at this site consisted of observations of two trial meetings, scrutiny of the responses by patients to the feasibility study, the successful bid and interviews with three of the four key professionals involved in the development of the funding bid and PPI process. The fourth professional was approached and agreed to be interviewed; unfortunately, scheduling problems prevented this from happening (see Table 4). The trial was just starting to recruit when my data collection phase ended. While a patient representative had been appointed by that stage they had been unable to attend the first data monitoring committee meeting. It was decided that as the representative was yet to be actively involved in this site it would not be appropriate to interview them.

Table 4: Child sites, participant information

Site	Pseudonym	Role	Basic biography
Child site one	Rachel	Professional	Research assistant, Psychology degree, 4/5 years' experience of researching this type of epilepsy condition, approx. 28 yrs. old
	Nick	Professional	Lead researcher, Reader and Honorary Neurology Consultant, specialised in epilepsy for ten years, extensive involvement with epilepsy charities
	Moira	Representative	'Sufferer' for 5 ½ yrs, set up a support group which is now a registered charity which she runs with husband Jim, 31 yrs. old
	Jim	Representative	Moira's husband and carer, Chairmen of a charity he founded and runs with Moira, 31 yrs. old
	Claire	Representative	'Sufferer', also had a number of physical and mental health conditions currently unemployed, 37 yrs. old
Child site two	Sue	Professional	Trial co-ordinator, first clinical trial, one previous research post which was related to epilepsy, 28 yrs. old
	Oliver	Professional	Practicing Neurologist and epilepsy specialist who identified the research question and was a co-applicant on the funding bid, approx. 35 yrs. old
	Bill	Professional	Primary investigator, medically trained as a doctor specialising in obstetrics and gynaecology, became an academic, experienced trialist, approx. 55 yrs. old

2.7.3 Sibling site one: comparator epilepsy network

In October 2004, prior to the establishment of the UKERN a government funded research network was established to create a multi-disciplinary and co-operative approach to epilepsy research in a designated region of the UK and to enhance best clinical and investigative practice in epilepsy. This network was selected as a study site for a variety of reasons; (i) it could provide a disease-specific comparator research network which used a different approach to PPI, (ii) it could provide insights into PPI activities in an already well-established network, which would not be possible from the UKERN, (iii) the UKERN drew upon this epilepsy network's structure and experiences during the early phases of its own development and (iv) it had overlapping aims and professional membership with the UKERN, making it part of the same 'story'.

The comparator epilepsy network (CEN) was made up of four research and development groups; Biomedical, Clinical, Health Professional and a Patient Forum. The Patient Forum was made up of 18 representatives, a coordinator (Jess) and a Neurologist (Tom), who met face-to-face approximately every three months, with email communication between meetings. The Patient Forum both consulted on projects for the rest of the network and identified its own research priorities. In contrast to the UKERN the representatives in the comparator network were not required to fit pre-specified criteria; rather anyone who wished to be involved could be, thus offering an insight into the potentially diverse experiences of different 'types' of representatives.

Due to geographical distance and the frequency of meetings, with the support of my supervisors, I decided that a one-off approach to exploring PPI in the comparator network would be most appropriate. Jess acted as a key informant and gate keeper. She provided me with copies of the minutes of all past meetings and examples of feedback the group had provided to researchers. She identified representatives who she believed reflected the spread of people and opinions within the group and arranged for me to interview them over a two day period either side of a patient forum meeting (two of the interviews were done in husband and wife pairs at their request) (see Table 5). She also drove me to the various interviews, meaning that in addition to the formal interview I undertook with her, I also had the opportunity to have extensive informal conversations that I documented in my fieldnotes. In addition to the representatives and Jess I also interviewed Tom and the Network Director, giving me both 'on the ground' and policy level perspectives on PPI in the

comparator network. My observation of the Patient Forum meeting was audio recorded and transcribed providing a more in-depth account of the meeting alongside the fieldnotes.

Table 5: Sibling site one, participant information

Site	Pseudonym	Role	Basic biography
Sibling site one	Tom	Professional	PhD student linked to the network, taking a break from his Neurologist training, clinical researcher, 32 yrs. old
	Jess	Professional	Network coordinator, completed an epilepsy related qualitative PhD, clinical practitioner, researcher, approx. 30 yrs. old
	Les	Professional	Network Director, genetics professor.
	Max	Representative	Retired, worked in skilled and academic occupations, diagnosed with epilepsy 20 yrs. ago, how controlled his epilepsy has been has varied over time. ⁸
	Matt	Representative	Support worker, working for ten years with people with learning difficulties, the majority of whom have epilepsy.
	James*	Representative	Retired head teacher, diagnosed with epilepsy 10 years ago, been on and off drugs in that time, relatively 'mild' and mostly controlled, 59 yrs. old
	Jill*	Representative	Retired teacher, James's wife, approx. 60 yrs. old
	Paul	Representative	Had epilepsy since he was 12yrs old, frequency of seizures has varied over time and medication, averages 1 seizure every 7 weeks, part of the British Epilepsy Association, had not yet attended a CEN meeting, 42 yrs. old
	Sam	Representative	Had epilepsy since he was 12, it was uncontrolled until he was 21 then 'controlled' until he was 55 now uncontrolled again leading to clinical depression. Successful career while controlled, one of his children has epilepsy and other medical difficulties, approx. 69 yrs. old
	Molly▲	Representative	Brother died from epilepsy aged 21, she has had epilepsy all her life, active fund raiser, cancer survivor and part of the cancer network. Two teenage children
Chris▲	Representative	Husband and career to Molly, had a work related head injury	

*▲ interviewed together.

⁸ *Controlled* seizures mean that the seizures have stopped having responded to treatment; *Uncontrolled* seizures are ones which continue, even though the person has tried one (or many) medications.

2.7.4 Sibling Site two: the UK topic specific research networks

As previously mentioned, the National Institute for Health Research (NIHR) established a Comprehensive Clinical Research Network (CCRN) in 2006 resulting in six topic-specific Clinical Research Networks and the Primary Care Research Network. Within these networks PPI was prioritised from the beginning, with designated funding attached to a PPI ‘lead’ role, which was mandatory in all networks. The CCRNs were included as a site in order to understand the broader context within which PPI is currently operationalised in UK health research and to gauge to what extent the findings obtained from the epilepsy sites are disease specific. The aim was not to generate a detailed understanding of the PPI processes implemented across the Networks (to do this, each of the seven networks would have to be treated as an individual site, which was outside of the scope and aims of this research). Rather the aim was to get an overview of PPI processes and an understanding of key issues. It was decided that this would be achieved by interviewing the PPI leads. All seven PPI leads in the CCRN were contacted via email, five responded and were interviewed, three face-to-face and two over the telephone (see Table 6).

Table 6: Sibling site two, participant information

Site	Pseudonym	Length of time in post ⁹
Sibling site two	Sarah	4 yrs.
	Owen	5 yrs.
	Lyn	6 months
	Fred	4 yrs.
	Charlie	2 yrs.
	Adele	6 yrs.

Although observation of the CCRN PPI leads at work was not part of my original research plan, I took advantage of opportunities that presented themselves. For example, I was able to observe a CCRN PPI network leads meeting and regularly interacted with some of the more locally based leads at PPI related meetings such as the North West People in Research Forum. Around the time I started data collection, the CCRN conducted an internal evaluation of PPI in the networks. This resulted in two key documents: ‘The Way Forward Report’ and the ‘Making a Difference Report’. These were both included in my data analysis.

⁹ It is not possible to provide more information and maintain anonymity due to the small number of people with this job role.

Figure 6 shows the timeline of data collection, highlighting which sites I was actively following at a given time. Table 7 provides a summary of the data collected across all sites.

Table 7: Data summary

Site	Data Type
UKERN	26 Observations 24 Interviews with 13 people 55 Documents Inc. 26 applications
Intervention study (CS1)	2 Observations 5 Interviews 15 Documents
Clinical trial (CS2)	2 Observations 3 Interviews 5 Documents
Comparator epilepsy network (SS1)	1 Observation 9 Interviews with 11 people 13 Documents
Network PPI leads (SS2)	4 Observations 6 Interviews 2 Documents
Total	35 Observations 47 Interviews 90 Documents

Figure 6: Timeline of data collection

	2010							2011						2012		
	Feb	May	June	July	Aug	Sep	Oct	Jan	Feb	April	June	Aug	Sep	Nov	Feb	March
UKERN	Launch	Selection of PPI Reps			Professionals Interviews	Training Day	First meeting with PPI Reps I---Reps interviews ---I CSG Leads Interviews					Reps interviews	Face-2-face meeting	Face-2-face meeting		Reps feedback meeting I--- Interviews ---I
Intervention study			First observation			Second observation		I--- Interviews ---I				Minutes		Interview		
Clinical trial								Feasibility survey			I--- Interviews ---I	Observation				
Comparator epilepsy network			Observation interviews													
Network PPI leads								Interviews								

Note: Blocked out sections represent when the site was being actively followed, Reps= representatives, only a sample of the UKERN observations are detailed in this figure.

2.8 Analysis: understanding my data

Qualitative data analysis is not seen as a discrete stage in the research process to be conducted once all data has been collected. Rather it is a pervasive and integrated activity throughout the research (Coffey & Atkinson, 1996). This is particularly important in ethnographic studies where later stages are generally dependent upon earlier ones. Gibbs (2008) argues that data analysis is essentially the interpretation of what is going on. Analysis therefore starts to take shape informally in the ethnographer’s analytical notes, initial ideas and hunches (Hammersley & Atkinson, 2003). Consequently the construction of my fieldnotes was part of the first stage of my analysis process (Fetterman, 2009), as I made sense of what I was observing and highlighted areas of interest to be followed up and further explored (see Figure 7).

Ethnographic analysis is an iterative process, building on ideas and perceived patterns throughout the study (Fetterman, 2009); with the continual development of theories, testing and funnelling of information, and becoming progressively more focused over time as ideas solidify and become more robust to testing (Hammersley & Atkinson, 2003). This must be done while paying attention to both the detail and the larger context (Fetterman, 2009). The time frame of my data collection and ethnographic approach reinforced the recursive nature of the analysis process and I was often simultaneously in different phases of the analysis process at a given time. Thematic Analysis, Grounded Theory, Interpretative Phenomenological Analysis (IPA) and Narrative Analysis can all be used within an ethnographic methodology (Cooper, 2012; Fetterman, 2009; Flick, 2009a; Silverman, 2006). I chose to use a thematic analysis as it allowed me to look both across and within sites and roles.

Figure 7: Data analysis process

	Stage One During data collection	Stage Two Focused analysis
Concurrently	Discussions with supervisors, colleagues & member checking	Discussions with supervisors & colleagues
	Fieldnotes: identifying possible patterns & areas of interest- testing these patterns	Focused thematic analysis
	Initial thematic coding- emphasis placed on comparator epilepsy network and participants undergoing multiple interviews.	Write up

2.8.1 Thematic Analysis

My analysis was based heavily on the work of Braun and Clarke (2006) and their step-by-step guide to thematic analysis. I chose this approach as it is more prescriptive than others while remaining flexible, is in line with my theoretical stance and addresses the research aims. Thematic analysis is a method for identifying, analysing and reporting patterns (or themes) within data. At its most basic level it organises and describes the data, with more sophisticated analysis interpreting aspects of the phenomenon under scrutiny (Boyatzis, 1998).

A common discourse within thematic analysis and qualitative analysis in general, is that of 'themes emerging' from the data during analysis. Taylor and Ussher (2001) argue that: "*Discursive themes do not just lay about waiting to be discovered, they do not simply emerge, but must be actively sought out*" (p.310). Braun and Clarke (2006) develop this idea further by highlighting that describing themes as 'emerging' presents analysis as a passive process and does not take into account the active role the researcher plays in identifying, selecting and reporting themes. This implies that the themes exist in the data independent of the researchers' interpretations, a position that is not consistent with a phenomenological stance. Braun and Clarke stress the point that thematic analysis is about making decisions regarding the data and recognising them as decisions.

Thematic analysis can be either deductive or inductive. Deductive analysis works from a pre-existing coding frame generated from theory or building on prior research. Inductive analysis generates themes from the data with no prior assumptions or framework (Boyatzis, 1998; Patton, 2002). As the purpose of this research was to explore the PPI process from the perspective of those involved, with the belief that currently little is 'known' in the literature, my analysis was an inductive one. All codes and themes originated from my interpretations of the data during the analysis process, with the research objectives as a guide. Figure 8 describes Braun and Clarke's (2006) six phases of thematic analysis which I used as the basis of my analysis. In addition, in keeping with the ethnographic approach, I viewed my fieldnotes as part of phase one (Hammersley & Atkinson, 2003) and viewed the process of writing as an 'analytical tool' to further data analysis and integration of related empirical literature (Hammersley & Atkinson, 2007). This placed greater importance on phase six than implied by Braun and Clarke.

Figure 8: Phases of thematic analysis, from Braun and Clarke (2006, p.87)

Phase	Description of Process
1. Familiarizing yourself with the data	Transcribing data, reading and re-reading the data, noting down initial ideas
2. Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code
3. Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes	Checking if the themes work in relation to the coded extracts and the entire data set, generating a thematic ‘map’ of the analysis.
5. Defining and naming themes	On-going analysis to refine the specifics of each theme and the overall story the analysis tells, generating clear definitions and names for each theme.
6. Producing the report	The final opportunity for analysis. Selection of vivid compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report.

As each interview was completed it was transcribed verbatim by a professional scribe. The decision not to transcribe the interviews myself – useful to facilitate the familiarisation process – was based on two factors. Firstly the number of interviews meant that transcription would be very time consuming and I might not be able to finish one set before the next round of interviews, affecting the iterative nature of the ethnography. Secondly the use of correct spelling, grammar and punctuation is extremely important during transcription as it can affect the meaning of and in turn the interpretation of a sentence. Achieving the required level of accuracy is outside of my abilities given my dyslexia. Once I received a completed transcript I checked it against the audio recording to ensure accuracy and anonymity.

As detailed in Section 2.6.1 alongside the formal, semi-structured interviews I also collected data in the form of fieldnotes from my observations and relevant documents. As I collected data they were combined in one NVivo database, making up my data corpus. Each piece of data was cross-referenced by site, type of data, type of participant (professional or representative) and pseudonym. This was necessary to manage the quantity of data collected and reduce the likelihood of information getting lost or missed. NVivo’s ‘query’ function allows for cross-referencing and pulls out information based on code and category. For example, it can pull out all data coded as ‘challenges’ within the representatives’ data, or data coded as ‘process’ in a given site. This made it easier to analyse the data as a whole and by sub-group, which was required for reasons that will become apparent later in this section.

Each type of data was treated in the same exact same manner. As it was imported into NVivo I read it through carefully (at least twice), recording any thoughts or ideas for further exploration using the 'memo' function (phase 1). During this time I also started to generate initial codes (phase 2). These early codes were very broad sweeping and loosely based on the interview questions, for example: benefits, challenges, motivations and understanding of PPI. Rather than adopting a grounded-theory, line-by-line coding method (Glaser & Strauss, 1974), I used a broader point-by-point approach to help keep the parts of the data linked to the whole (Riessman, 2008). The time frame of the data collection (see Figure 6) meant that I was able to do preliminary coding of the data from the comparator epilepsy network prior to conducting interviews at other sites. After reviewing these initial codes and reading over the 'memos' I started to identify possible areas of interest (phase 3), to explore further during subsequent observations and interviews (phase 4). Throughout my data collection period I cycled through phases 1-4 as new data was collected. I went through preliminary coding and I identified potential areas of interest that were then explored. Alongside regular reflective discussions with my supervisors (one of whom, as noted, was also a primary informant), I had many opportunities to explore and test my developing theories with different participants across different sites, both formally as part of interviews and informally during unstructured conversations, providing a consistent form of member checking. I prioritised analysing data from participants who were interviewed at multiple time points and keeping track of potential themes or things to 'follow-up on' in my fieldnotes to ensure that later interviews were grounded in, and developed from, pre-existing data. One of the main advantages of conducting multiple interviews was that it gave me an opportunity to clarify any ambiguity arising from preceding interviews in subsequent ones. This iterative method of analysis meant that both my fieldnotes and interview data became enmeshed as information from the fieldnotes helped to determine interview questions, and participants responses in interviews affected what I focused on during my observations.

Consequently, by the end of my data collection period I was already very familiar with the data and had developed ideas about codes and themes for when I shifted to a period of more focused and intense analysis. Building on the preceding analysis the whole data corpus was re-read and coded. I felt that this was particularly important as some of the earlier data had not been looked at in light of later insights and codes. By this stage of the process the codes were less linked to the original topic guide and were more detailed. For

example, rather than just coding data as a 'challenge', it was also coded by 'type' of challenge, which by this stage of the analysis consisted of 43 sub-codes that I had identified over the course of the data collection and analysis process. By the end of the data analysis process as a whole there were 109 codes and 169 sub codes, although it needs to be noted that many of the codes heavily overlapped.

Having established this overview of the data corpus I started to define and name themes within the data (Phase 5). It became apparent to me that there were four main areas of interest that I then pursued by conducting more focused analysis.

The first area of interest and analysis concentrated on data related to the PPI processes within each of the sites (this was largely based on the professionals' data and fieldnotes). Drawing on the questions, what did they actually do? and why did they do it?, this helped to address research objective 1: *'To describe how PPI was implemented within the specific context of the UKERN, and in the research linked to this network'*, and to provide a context for the rest of the findings (see Chapter 3). The second area of interest and analysis drew exclusively on data from the professionals to explore their experiences and views of PPI. The findings of this analysis are presented in Chapter 4. The same process was then repeated with the focus on the representatives for the third analysis (see Chapter 5) thus addressing research objective 3: *'to describe the experiences of the representatives and professionals involved in the PPI process, including their perceptions of the benefits and challenges of PPI'*.

During the second and third focused analysis the professionals and representatives were initially treated as a cohesive group. The data was then further analysed to look at the experiences across and within sites, this was part of the fourth 'synthesis' analysis. As explained in section 2.3 the hermeneutic circle moves between interpretations of the parts of a phenomenon under study and the whole (Chadderton, 1994) so that by systematically exploring the whole, new insights and an increased depth of understanding of the phenomenon will be produced. This information is then used to examine the sub-components of the phenomenon, in turn resulting in new understandings that need to be re-explored in terms of the whole (Leonard, 1994). I drew on the premise of the hermeneutic circle during the fourth analysis in order to address objective 4: *'to compare different approaches of implementing PPI, by contrasting the experiences of the professionals and representatives across the different research sites'*. As insights were

gained from the three sub- components or themes they were then used to examine my data as a whole. For example was there any consistency across all the groups about what were considered essential aspects of PPI? Was there any consistency in the decision making process about the approaches to PPI adopted by each of the sites? Where was there dissidence in opinion? Was there any anomalous information that provided insight into a majority view? As I developed my understanding of PPI in my sites as a whole this information was then evaluated and re-tested within the sub-components, which in turn fed into my understanding of the whole. This continued until I had reached the point that I considered 'optimal understanding' (see Chapter 6).

My ideas were developed through discussions of my findings with my supervisors, informal discussions with my colleagues and presenting at the PhD data analysis sessions in my department. These meetings provided me with space to step back from the data and to obtain the opinions of others not immersed in it. This was invaluable as it helped me evaluate and justify the decisions I was making with regard to my analysis.

As identified by Broun and Clarke (2006) the 6th phase of a thematic analysis is producing the report. In writing my results chapters I was continually refining themes, making decisions regarding which themes and codes were pertinent, linking them to each other, to the research question and relevant literature. It was also the point at which I had to choose which extracts in my substantial data set most supported my findings. During the concentrated data analysis process I found that the data from documents was not, on the whole, as pertinent as that from interviews and fieldnotes. While in some cases they gave insight into process, they gave little understanding of people's experiences and perceptions. Consequently they are only sparsely represented in the following results chapters. As previously mentioned my fieldnotes were enmeshed with my interviews, many of the issues identified in my fieldnotes were discussed directly with participants in the formal interviews. In presenting my data in the following chapters, I have prioritised examples of findings from the interview data over that of fieldnotes as it allows for more of the results to be supported by participants' own words.

2.8.2 Presentation of data

For stylistic purposes and ease of reading, quotes presented in the results chapters have been ‘tidied up’ of some of the hesitations and repetitions, while still maintaining their integrity. For example, ‘umm ere er uummm I guess’ is presented as ‘ummm er I guess’ or ‘I don’t know, don’t know ur I suppose I don’t know the answer’ is reported as ‘don’t know.... ur I suppose I don’t know the answer’. The quotes are formatted based on recommendations in British Psychology Association style guide (2004), Table 8 describes the transcription symbols used. The number of quotes used to support the findings varies as a result of the number of participants linked to a given point and the level of divergence in the related quotes.

Table 8: Transcription symbols

Symbol	Meaning
....	Brief pause
..[..]..	Jumps to a latter point in the same transcript
[No.]	Timed pause in seconds
[]	Additional information to make the quote clearer
‘ ‘	Indirect or approximate quote
“ “	Direct quote
(())	Description of something that cannot be transcribed verbatim.
‘Text in Grey’	Data from Documents and Fieldnotes

2.9 Ethical Considerations

This research complied fully with the ethical practice guidelines laid out by the British Psychology Association and the University of Liverpool. After a detailed discussion with the chair of the local NHS Ethics Panel and the University of Liverpool Ethics Board, it was agreed that the project did not require NHS ethics committee approval and should be vetted though the University Ethics Board (See Appendix 5). While some participants were working as clinicians within the NHS or were patients in the NHS system, they were not approached in these capacities; instead they were approached in their roles as academic researchers and individuals with epilepsy and/or an interest in epilepsy research. Consequently, the research was deemed to lie outside the remit of NHS ethics. The ethnographic nature of this research meant that additional attention was paid to issues

surrounding informed consent and anonymity, for reasons explained in the following two sections.

2.9.1 Informed consent

All participants who were interviewed gave signed, informed consent. Prior to consent they were provided with an information sheet about the study (see Appendix 6). They were also given time to discuss the study with myself or anyone else they wished to. They were told that they could withdraw their consent and leave the study at any time without giving a reason. Consent for audio-recording the interviews and fieldnotes was included within the consent form.

Consent for observations was sought from the person facilitating the event. All participants gave informed verbal consent at the beginning of each observation, but written consent was only obtained from the facilitator. At no point were the observations covert or conducted without all participants' knowledge.

Informed consent within an ethnographic study has to be considered differently to the standard anticipatory regulatory regimes that take place in most research processes (Murphy & Dingwall, 2007). As the ethnographic research process evolves the questions being asked may change and the levels of access can expand and therefore cannot be completely agreed to in advance (Parker, 2007). Therefore in addition to the standard forms, consent in an ethnographic study is a sequential process and must be revisited throughout the duration of the research (Murphy, Dingwall, Greatbatch, Parker, & Watson, 1998). Although the wording of the participant information sheet described the developing nature of the study, particular attention was paid to ensuring that participants were aware of any changes within the study and that they were still happy to give their consent. Where participants were interviewed more than once, I reconfirmed their consent at the start of each interview.

2.9.2 Data Protection and Anonymity

The research complied with the Data Protection Act of 1998, concerning the handling, processing and storage of the study data. All data (consent forms, audio-recording devices, fieldnotes, interview transcripts etc.) were kept secure in locked filing cabinets and the data used in the write-up was anonymised using pseudonyms and the removal of any identifying features such as names and places. This was also the case for any fieldnotes that others

might have access to. In situations where it might not be possible to completely anonymise data, for example where there was only one person in a specific role within one of the organisations in the study, this was addressed either at the data analysis stage or through consultation with the individual concerned. Particular care had to be taken when asking participants their views about issues that had arisen, as it might be possible for others within my sites to guess who I was referring to. That I was following more than one group helped with this as I could generalise to outside of individual sites.

2.10 PPI in this PhD

In accordance with the ethos of this research I considered it important that the perspectives of patient and public representatives were considered at multiple stages in my research process. It was hoped that such involvement would help to ensure the relevance of the PhD research, give a measure of validity and help to address any emerging methodological issues. As both professionals and representatives are potential users of this research it was important that both groups' views were obtained.

As previously stated ethnography is an iterative method with information from each step informing the next. Accordingly, research participants continually shaped the research questions and process. For example, if one participant highlighted something as important it could be integrated into the topic guides for subsequent interviews. Therefore it can be argued that all participants had a collaborative role within this research. It was also considered important to provide discrete opportunities for patients and the public external to the research to give feedback on the research as a whole.

Due to time and resource constraints I considered it appropriate to gain initial feedback about my research ideas, aims and methods from a pre-existing PPI group, rather than establishing a new group of individuals. Epilepsy Action (EA) is a registered charity providing a range of support for people with or affected by epilepsy. EA hosts a member-based group, the Epilepsy Action Research Network (EARN), which is composed of representatives tasked with giving feedback on grant applications submitted to the charity and input into other related research projects.

The consultation with EARN members took place approximately four months into data collection. This allowed the topic guides and research focus to be developed during initial interviews and observations before obtaining feedback on them, while still providing time

for the representatives' views to be integrated into the project. In consultation with the EARN coordinator, a letter was drafted to the group outlining the research and its aims. Enclosed with the covering letter was a feedback sheet asking for their opinion on the plain English abstract, the groups of people that might be interviewed, the draft interview topic guides and the relevance of the study (see Appendix 7). Feedback was received from 20 EARN members, with 14 agreeing to be contacted again if needed in the future. The comments I received from the EARN members helped me to clarify different aspects of the plain English abstract, validate the research questions and highlight a potential additional group of participants.

2.11 Summary

Epilepsy, and more specifically the UKERN, was chosen as the context in which to: *Generate a detailed understanding of patient and public involvement in health research*. This was achieved by using a multi-sited ethnographic approach which addressed both the research aims and my theoretical positioning. In line with the chosen methodology data were collected using a variety of methods including informal interviews, semi-structured interviews, observations and fieldnotes, which were thematically analysed. The data were divided into three broad analysis groupings: process, professionals' experiences and representatives' experiences. These are each addressed in turn in the following three chapters.

Chapter 3. How PPI was operationalised

3.1 Introduction

In Chapter 2 I emphasised that the ethos of a multi-sited ethnography is not to carve out one part of the story but rather to try to look at the whole, as each part is intricately linked to the others around it. This, I found, held true when I was conducting my data analysis. When trying to separate out the experiences of the professionals from those of the representatives, or from the process, I quickly learnt that the one does not make sense without consideration of the others. The perceptions of the professionals influenced their approach to PPI, different approaches resulted in different experiences, the experiences of professionals and representatives directly impacted on their counterparts, and their experiences in turn confirmed or changed the perceptions of those involved. However, to: *'describe the experiences of the people involved in the PPI process, including their perceptions of the benefits and challenges of PPI'* (Objective 1) or: *'to compare different approaches to implementing PPI'* (Objective 4) it seemed important to first separately explore how PPI was implemented in the UKERN and in each of the sites. To give an insight into what it means to 'do PPI' and provide the context for later explorations of the data, in this chapter I describe and interpret the process that each of the epilepsy related sites undertook in setting up and implementing PPI, highlighting key aspects of the decision making process and the factors that were of importance to them.

Once I have described the site specific PPI processes I then go on to explore some of the commonalities and differences across the different approaches. Throughout this chapter I largely focus on the information I obtained through interviews and observations with the key professionals at each site. The reason for this is that they were involved in each stage of the process and as such had access to aspects of the PPI process that the representatives were not involved in. They were also nearly entirely responsible for any choices made around PPI in their site and as such, in this context, their explanations in general, provide more insights into the development of the PPI approach and decision making processes than those of the representatives. However, I draw on information from the representatives whenever their perspectives enhance the description of the process.

In Chapter 2 I explained that sibling site two, the UK topic specific research networks, was approached differently to the other sites. The aim of including it was to provide an

overview of PPI experiences and an understanding of the perceptions of the key issues among the Network PPI Leads, who had considerable experience of implementing PPI, rather than to generate a detailed understanding of the particular PPI processes they had implemented. Given this and that my research objectives focus specifically on describing PPI in *epilepsy* research, data from sibling site two is not described in this chapter, but is considered in Chapter 4.

The comparator epilepsy network (CEN) was established prior to the UKERN; as such the UKERN drew on the CEN when developing its own process. Therefore to fully explain the PPI process within the UKERN, it is necessary to first describe the approach to PPI in the CEN. This ordering also feels particularly appropriate to me as the CEN is the first site that I completed.

3.2 Sibling site one: comparator epilepsy network

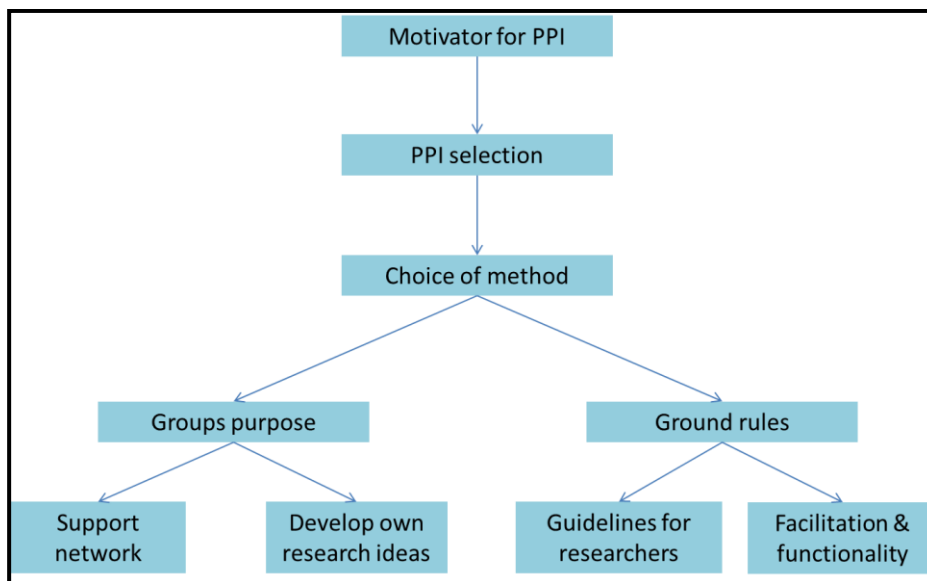
As I explained, in this chapter I am mainly drawing upon the interviews and observations I conducted with the lead professionals; within this site they consisted of Les, Jess and Tom. Les, a Professor of Genetics, was the founder of the network and as such was able to offer a unique insight into its inception and initial stages. He acknowledged that he knew little about the day to day functioning of the patient group but in line with his role he had clear ideas about its purpose and how it was perceived within the Network as a whole. Jess, the Network Coordinator, had been in post since funding for the network had been obtained five years previously. Part of her role was to set up and facilitate PPI within the network. Alongside this she co-ordinated the rest of the network and completed an epilepsy related, qualitative PhD. At the initiation of her role she had no previous PPI experience. Tom was a PhD student linked to the network. He had taken a break from his Neurologist training to focus on researching epilepsy and viewed himself as Jess's helper, taking the role of the: "*non-threatening clinician*" (Tom) within the group. He had sat on groups with patient representatives before but this was the first time he had taken an active role in enabling PPI.

During the first year of the network three research development groups (RDGs) were formed. The close knit nature of the professional epilepsy community meant that they: "*already knew who might want to get involved*" (Jess). Once the RDGs had been established attention was given to PPI. Les explained that the purpose of the network was to involve as many different people as possible in epilepsy research: "*because of the nature of the*

funding call as well, where involving people was at the centre of one of its core principles” and as such PPI was integrated into the aims of the network: *“well, on the mission statement, our network is a collection of scientists, clinicians and patients in partnership”* (Tom). Drawing on this core principle of partnership the lack of patient and public representative presence within the network was seen as something that needed to be addressed: *“a discussion in 2004, myself and there was about 10 other people including epilepsy nurses, and we just decided this would be a good idea”* (Les).

What makes this site different from the others I studied is that other than knowing they wanted representatives to become part of the network the researchers: *“didn’t have strong ideas about what we might get from it, and so without that kind of, the constraint of about how to set it up”* (Tom). In addition, Jess’s lack of knowledge and experience of PPI meant that she did not have any preconceptions about the best method of implementing PPI. Consequently, she took a very different approach to establishing PPI than the other sites (see Figure 9).

Figure 9: PPI process in comparator epilepsy network



Synonymous with how she coordinated the professionals RDGs, Jess started by contacting representatives who she identified might be interested in being involved. These firstly consisted of people who either Jess or her colleagues had met during the course of other projects and who had also expressed an interest in further involvement in the research process: *“we had met lots of really lovely, really interested people who were always saying ‘oh if there is anything else I can help with if you are doing any other research let me know”*

(Jess). She also contacted epilepsy nurses and clinicians asking: *“do you know of anybody who would like to attend this sort of thing?”* (Tom). She asked the identified people if they would like to: *“come along and sit perhaps on the other RDGs and kind of be a representative”* (Jess). The representatives, however, did not wish to sit on the other RDGs. They told Jess they wanted their own group, in order to have an opportunity to consider their own research questions, something that they did not feel would happen if they were integrated into the other groups:

“The feedback we got said that is not really what they wanted to do, they would much rather have their own research development group, that they had lots of ideas, and instead of being a representative on somebody else’s group they would really like to have their own group so, I guess that is where it all started from.” (Jess)

This request for their own patient RDG was supported by Jess, Les and Tom’s belief that representatives would be more confident, and therefore more likely to have honest input to group discussions, if they were surrounded by other representatives as opposed to being outnumbered by professionals.

It was decided not to have any selection criteria for membership to the patient RDG, rather anyone who wished to be involved could be: *“we sat down at the beginning and decided whether or not we should place restrictions on who should come to the RDG or try and select and in the end we decided not to”* (Jess). Jess believed that if they were to have selection criteria they would only include individuals with academic ability and extensive research knowledge. While this would have been advantageous in terms of applying for funding and conducting research, Jess felt that such representatives would not be genuinely ‘representative’ of the epilepsy community as a whole. As such it would go against the ethos of the network which was to include anyone interested in epilepsy research:

“If I was looking back to when we were thinking whether we should set limits, I guess we were thinking about people who understood research, who were academically able enough to perhaps write papers with us, or review things properly. So I guess that was the kind of the people we, we might have constrained it to. But again, even then it was obvious that they weren’t the kind of people, ok, so there are people like that who have epilepsy, of course there are, but there are lots of people who aren’t like that, that have epilepsy so, I guess that’s why we chose not to do it because they would be representative of their own kind of people, not of people with epilepsy. Yeh, does that make sense?” (Jess)

Les and Tom also placed considerable importance on the ‘representativeness’ of the representatives. In line with this it was not just patients that became part of the group but family members and friends as well. The group was extremely varied in terms of experience

and ability and while Tom acknowledged that the group could never be truly representative, he felt that they were as close to achieving that as possible:

“You know we couldn’t hope to get a genuine variety of experiences with only 16 people or 20 people or a wider group. You know we don’t permanently have somebody who is pregnant on the group; we haven’t gone out looking for a complete balance. Um, we don’t have children on the group you know, but I think within the naturalistic style of the way that it was created, urm, that the scope is very fitting actually, I think it’s very suitable.”

The lack of a clearly defined purpose for the group initially meant that the first few meetings revolved around establishing how the group was going to work and what they wanted to address. Jess and Tom admitted that this was difficult to begin with as they did not want to dictate how the group functioned, as the representatives had ownership of the group. At the same time the representatives needed Jess’s and Tom’s knowledge to make the group work:

“Some people [representatives] were a little bemused, I think some people just gave up their time, because it was a good thing and didn’t really know what they were giving up their time for, didn’t know, even after a couple of meetings what this was, you know whether they were, you know had power, whether they had money to spend, uerm whether they had a bigger role.” (Tom)

Jess reflected that the way she dealt with this uncertainty was to be honest with the representatives that she was not clear about how the group was going to work and that they would have establish together what they wanted out of the group and how they were going to achieve it:

“It’s been a real learning curve both for us and for the patients, and the people who come to the group as well. But I hope from the very beginning we have been really honest about that and kind of, very clear that this is a journey that we are on together, and it’s, it’s not going to be perfect straight away and there is work to do.” (Jess)

Originally there was meant to be a different representative acting as Chair of each meeting, but this proved to be problematic because under this system the group did not manage to cover everything on the agenda, so Jess took over managing the meetings:

“Ahh although we have a patient chair, Jess has to chair it because, it has come to pass that Jess has to be ipso facto chair, because of time and structure and she is much more familiar with the mechanics of how the meeting runs, and leaving it to the elected patient chair, er it didn’t keep the kind of structure that would make sure you, could do everything within the time allotted.” (Tom)

The meeting that I observed was the group’s sixth. By this time the members had worked out how they wanted the meetings to run. The group decided to meet approximately once every three months and to considered itself as having two main functions. The first was to

provide feedback to the other RDGs about their projects and the second was to develop their own research ideas. It quickly became evident to those involved that the two hour time slot given to each meeting was not sufficient to cover everything and to accommodate the diverse range of personalities and abilities of the group. It was decided that the majority of work would be done outside of the official face-to face meetings, either by email or in smaller working groups:

“We decided that most of the actual work would go on outside those meetings. So what we will sometimes do is we will say right, we are thinking about putting a grant application in on this subject, if you would like to be involved let us know and we will arrange a meeting outside this time. Or if we get asked, um, to review patient information sheets or consent forms and stuff, we will send round the group and say if you can within the next few weeks can you let us have your feedback, and the meetings have become just a really nice opportunity for all the members to get together, throw research ideas around, perhaps getting someone to come and talk about their work, catch up with each other and I guess just be in that kind of stimulating environment.” (Jess)

Another thing that quickly became apparent was the need to establish guidelines for researchers who wanted feedback from the group. In the beginning the group were frustrated with how little time they had to return their feedback, as often the researchers approaching them were working to an imminent deadline. They needed to explain to the rest of the network that the group could not function efficiently like that and if they were only given 48 hours’ notice it was likely that only one or two members would be able to give cursory feedback. Alternatively, if they were given, say, three weeks most people would have time to give detailed responses. The representatives suggested to Jess that they would have an easier time providing feedback if researchers came to the group in advance and talked about their research in general so that they could place the information that they were looking at in context. Consequently the first half of the meetings normally consisted of a guest speaker:

“They have then elected to have people come and just talk about their research in general, so we talked about brain imaging in general, um so people can ask questions about it, understand his, you know why look at the brain, why at the concept level so that when he comes in a year’s time, 3 years’ time, with projects you sort of understand him and the reason why.” (Tom)

Over dinner after the meeting that I attended, Tom remarked that: *‘one of the speakers had acknowledged that this was particularly beneficial for him as he did not think he would be able to leave enough time when writing grant applications to get feedback outside of the meeting, but he could incorporate what he had learnt during the group discussion’* (paraphrased in fieldnotes) thus making the group work for him.

The second half of the meetings were dedicated to discussions around the representatives' own research ideas. They found the most productive way to achieve this was for one representative per meeting to put forward their idea and get feedback from the group. The less confident representatives found it reassuring that they could pass their ideas though Jess outside of the group first. Although they had not yet been successful in taking any of these research ideas past the grant application stage the group was optimistic that they had ideas worth pursuing.

The choice not to screen the representatives prior to recruiting them to the group combined with some of the problems associated with having epilepsy meant that there were some difficulties within the group:

“Maybe up to a third of people with epilepsy will have mood problems in their lifetime. Some people with epilepsy have learning difficulties; some people may have problems with concentration and memory. That probably describes the normal population as well, but it doesn't always fit in well with, um, getting on with other people, sticking to structure, that sort of thing. We have got one member of the group who erm had a [name of condition], who the rest of the group have learnt to deal with well, but in the first couple of groups he would cut across everything because he would stick to a certain idea and keep on saying it and be out of kilter with everything going on around him, and he would stick to his routines. All great behaviours but not at the right time, or the right place in the meeting.” (Tom)

However, the consistency of the group membership meant that the less socially comfortable representatives were able to get to know the others around them, making them feel more confident in the group setting and increasing the likelihood they would contribute (see Section 5.4). Also by learning about each other's quirks and foibles the group was able to self-manage their dynamics to reduce disruptions:

“By not changing the number, the faces around the table all that much, people have learnt how to get on with each other well, so it's not as disruptive, as it was, or as it could be.” (Tom)

I feel it is important to say here that both Jess and Tom were adamant that they had made the correct decision to be inclusive in terms of group membership. They felt that the information that came from the group more than made up for issues in social dynamics and that often the most disruptive individuals made the most insightful comments.

Jess felt that one of the most difficult things about their approach to PPI was the fact only herself and Tom had the skills and responsibility to act upon the information the group was producing, for example writing grant applications or following up lines of enquiry. As facilitating the group was only part of her role and in Tom's case his input was largely

voluntary, they could not dedicate the amount of time to the group that they felt it deserved:

“We don’t have the capacity to do this properly. If we were going to do this properly I would want somebody devoted to the patient RDG, at least 2 days a week so that they could be in touch, every week just to say how is everybody, em so that there was always somebody who was at the other end of the phone if they had any questions but also there are so many good ideas that come out of the patient RDG that me and Tom just don’t have the capacity to sit there and write grant applications just solely for what comes out... ideally I would like somebody sat writing applications every day based on what the patient RDG does..... I think that’s my biggest flip side. That I feel constantly we are just not doing enough, that they give us so much, and we are working at capacity but we just can’t deliver on everything that they want us to deliver on.” (Jess)

“We really like a project that someone is offering, bubbling under, because it’s working out, if I am giving up my time voluntary, how do I then slot her research project into my work time? Is it, should it be me? How do we facilitate, you know getting her project off the ground and writing it properly without stealing her ideas, or without twisting them into a form she had never identified in the first place.” (Tom)

To address this problem the network was applying for additional funding to allow more research support to be dedicated to the patient group.

One problem that Jess and Tom felt had permeated the group from the first meeting was how uncomfortable they felt about the difference they perceived between how the group was meant to run in theory and how it operated in practice. This was demonstrated earlier in relation to how the group made decisions about how they would function and who acted as the facilitator. The ethos of the group was that it belonged to the representatives and as such both the representatives and the professionals were presented as being equal stakeholders. In many respects this was not truly the case, with Jess and Tom having responsibility over the agenda and the outputs:

“You are saying it’s all equal, it’s all level playing fields but Jess is producing the agenda so she knows what is happening and she is not including extraneous things.” (Tom)

Also, due to their professional codes of conduct with members of the public, they did not feel they treated the representatives in the same way as they would other colleagues and this: “*small bit of dishonesty*” (Tom) did not sit well with either Jess or Tom. Dealing with the blurring of their professional boundaries and roles was stressed by both Jess and Tom as one of the most challenging aspects of this form of PPI. Challenges around roles were also raised by some professionals in the other sites and I discuss them in more depth in Chapter 4 (see Section 4.5.4). However, the particular purpose and the social dynamics of

the CEN seemed to exacerbate these issues in a way the other PPI approaches did not appear to.

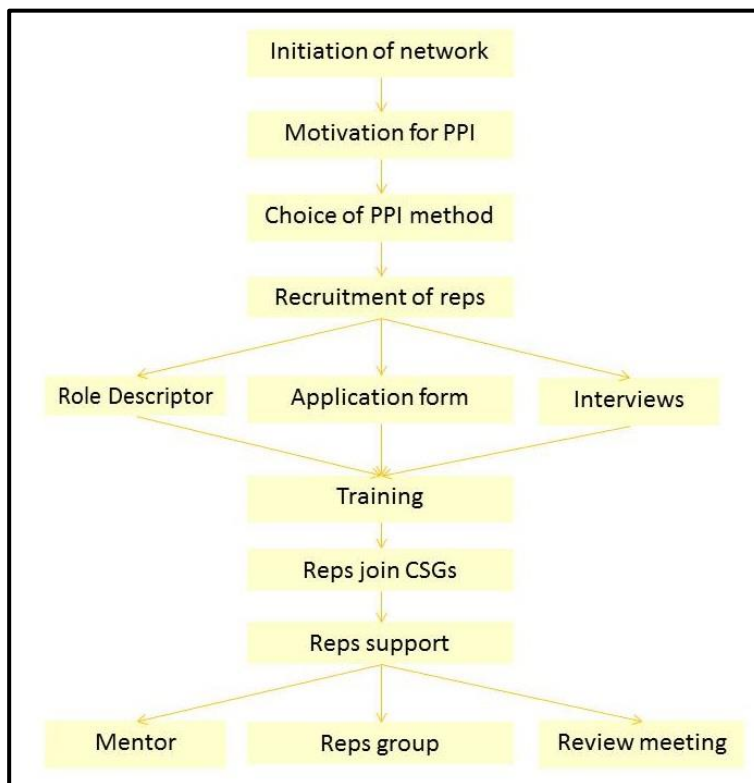
3.3 Main study site: the UKERN

PPI in the comparator epilepsy network and other sites (as discussed in Sections 3.4 & 3.5) was largely dependent upon the work of two or three professionals. The UKERN took a more collaborative approach and as such there were eight professionals who played a key role in the development and execution of PPI within this network (see Table 9). The influence of each person changed throughout the stages of the approach (see Figure 10) and this is reflected in my description of the process.

Table 9: UKERN key PPI professionals

Pseudonym	Role
Emma & Lucy	Epilepsy charity research leads
Alex	Network Director
Ann	Network member, PPI specialist & primary supervisor of my PhD
Angela	Network coordinator
Francis, Lee & David	CSG leads

Figure 10: PPI Process in UKERN



The other key difference about this site compared to the others described in this chapter is that I was able to observe the majority of the events discussed and, as I explained in my methods section, I never formally interviewed Ann one of my key informants. Consequently, I draw more on my fieldnotes in this section than I have when discussing the other sites in this chapter.

According to Alex and Emma PPI in the network was initiated during the first exploratory meeting at which the idea of establishing such a network was discussed. This meeting, which consisted of researchers, epilepsy charities and other potential stakeholders, discussed the viability of setting up a UK-wide epilepsy research network (both Alex and Emma were in attendance). Once attendees expressed genuine commitment to developing a network, they looked to the established comparator network for a template. The UKERN adapted the three RDG structure to form three clinical study groups (CSGs), with each group focusing on a different part of the epilepsy journey. Understandably, when discussing the comparator networks' structure, the idea of a patient group was raised and PPI as a broad issue was discussed. What I understood from Alex and Emma was that while some members of the group were not PPI enthusiasts, as a whole, they were easily in agreement that there should be PPI in the network.

Emma felt that it was Alex's support for PPI that led to it being integral within the network. As such I feel his motivation and perceptions of PPI are particularly salient in understanding how and why PPI was implemented in the UKERN. When asked, Alex said that the purpose of PPI in the network was to: *"make sure that the research is relevant to patients and the public"*. One of the aims of the network was to identify and prioritise gaps in epilepsy research for further investigation. As such, anything that might contribute to the relevance, importance and usability of the identified research priorities would be seen as beneficial. Lucy also raised the point that the network was largely publicly funded through charities, placing emphasis on the moral and ethical motivations for PPI as discussed in Chapter 1 i.e. if the public are paying for the network they should have a say in it.

Unlike the comparator epilepsy network, Alex made the decision to have representatives on each of the CSGs as opposed to having a standalone representative group. This decision was largely championed by Emma:

"There was a proposal about having a separate user group because that's the Comparator Network's [my wording] model and I said no, don't do that, that's you know, to me I felt that was completely wrong, so I was very vocal about it and I said I

think there should be user involvement on the panels and should be, have sort of equal part in there.” (Emma)

Emma felt that having patients in a separate group would be tokenistic, reduce their involvement and their potential impact in the network. This position was supported by Lucy and Ann, who as PPI experts were also influential in Alex’s decision. Lucy felt that if the representatives were in a separate group they would not be integrated and in turn not truly involved. Ann stressed her belief that without a ‘substantial professional presence’ within the same group as the representatives, nothing a representative said would be acted upon. Emma summarised many of these points:

“I felt that looking in the longer term that wouldn’t achieve anything, because that group would meet to discuss research but erm, [04] how would a, would the discussions from that group have sufficient influence on network sort of strategy, that was one of my concerns and it seemed very tokenistic you know to siphon service, you know users away into one little group for them to talk amongst themselves. It just seemed very, very old fashioned and, and, and just, completely wrong to me. Er because I felt that they should be er treated as equals.

As I elaborate below, the UKERN members were working from a very different stance to the comparator epilepsy network in terms of their perception of what is and is not involvement. Alex had no clear preference and as the PPI experts felt so strongly he said it: *“just seemed like the way to go”*.

Convictions about what constitutes ‘real’ or ‘meaningful’ involvement appeared to be at the core of this group’s PPI decision making. Throughout the observations and interviews there was a sense that all the UKERN professionals were in agreement and viewed their method as self-evident and logical, with a perception that no other method would have made sense in this context. The choice of six representatives resulted from suggestions in best practice guidelines and past experience which indicated that: *“we would recommend that you have more than one person [per group]”* (Lucy). Given this, and taking into account the size of the CSGs (core group of around 10 people with individual specialisms), it seemed to follow that there should be two representatives per group. The UKERN professionals did not think it was possible for six people to be representative of the epilepsy community, so this was not an aim in the representative selection process: *“it’s just the nature of the beast ...[.]... you can never be representative I don’t think”* (Lucy). Instead, emphasis was placed on having individuals who would be able to make a ‘meaningful’ contribution. By ‘meaningful’ they meant that the representatives would be able to actively interact with other network members and not be intimidated into silence when surrounded by academics and medical professionals: *“If you are going to have any form of, erm, lay*

representation that is meaningful you probably need to go for people who are articulate” (Emma). Conversely having representatives who were not able to function in this environment was viewed as futile: *“You know there is no point in setting, putting somebody up in a situation where they are not going to be able to contribute”* (Lucy).

The decision to have two representatives on each CSG group was put forward to the CSG leads during the first Management Group (MG) meeting which took place at the UKERN launch: *“Alex informed the MG that he envisioned having two patient / public members per CSG, and potentially a patient / public member on the Management Group sometime in the future”* (Extract from MG minutes). The structure of the day meant that after introductory talks the CSG groups met for the first time. During the inaugural meetings they agreed to meet every three months via teleconference and at least once a year face-to-face. They also discussed the purpose of the groups and elected group leaders, who then proceeded to participate in the management group meeting. Patient and public involvement was the third item on the agenda in the first MG and issues such as payment, selection and role of representatives were discussed:

“It was suggested that one role for patient/ public members could be to look over publications resulting from UKERN-supported studies and comment on their readability. Alex reminded the group that the time these members spent on this would need to be budgeted for. ..[.]. Lee added that it is very important to get the right people applying for PPI, who are genuinely interested in epilepsy research (not there for their own agenda). Alex agreed that this warranted further discussion.” (Extract from MG minutes)

It was also during this meeting the issue of the training and mentorship for representatives was raised for the first time, with the group as a whole agreeing that both were important:

“Lucy highlighted the importance of training patient/ public members in preparation for CSG participation. All agreed that knowledge of epilepsy research and how to contribute to the CSG (and CSG meetings) were emphasised as key training points. The idea of having one or two people within each CSG act as mentors for patient/ public members was also discussed.” (Extract from MG minutes)

After this meeting Lucy developed a role descriptor and application form for representative candidates to complete. The reasoning behind this formal application process was that, combined with interviews, this was the most effective way to determine if someone would be able to function within the group. It was also seen as the fairest way to select representatives. By advertising for representatives on different websites and using word of mouth, more people had the opportunity to apply, not just representatives already known to the professionals. Constructing the role description also was seen as having the added

bonus of forcing the CSG leads and network professionals to be clear on what they viewed the representative roles to be within the group:

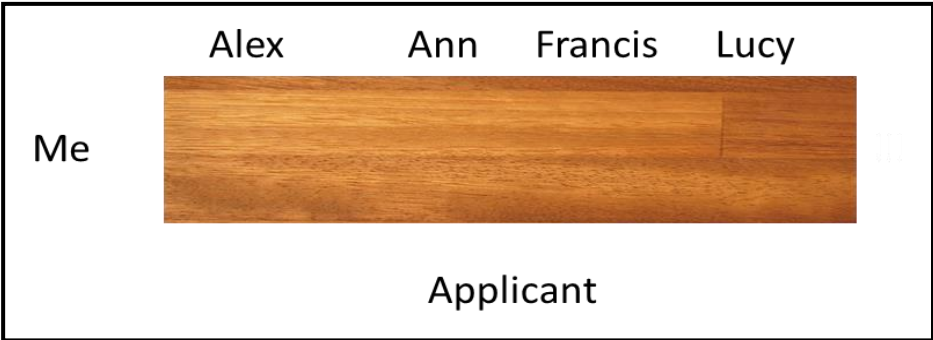
“I couldn’t think of another way of doing it. If you are asking people to fulfil a role then they have to know what that role is..[...]...so that you know that people are able to fulfil that role, and that is from say our side, but from the side of the person then they know what is expected of them. So I think we went about it the right way, I think it was good practice.” (Lucy)

The role descriptor and application form were approved by Alex and the CSG leads after a few adjustments by Ann. The application form mainly consisted of two open ended questions:

- 1. Having read the role description please tell us, giving examples, how you believe that your skills and experiences would enable you to fulfil this role. Please also explain your interest in epilepsy research and your reasons for wanting to work with the Clinical Study Group(s) you have indicated. (750 words max)
- 2. Please describe any training you feel you would need to support you in this role.

Twenty six people applied for the posts and nine were shortlisted for interview. Alex, Ann, Francis (one of the CSG leads) and Lucy conducted the interviews. With the applicants’ permission I was also in the room. While the representatives were all happy to be interviewed (it follows that if they had not they would not have applied) and felt that it was important, some of them did remark that it was somewhat intimidating and much more formal than they were expecting for a volunteer position (see Figure 11). Each of the interviewers had a scoring sheet and after all the interviews were conducted the scores were totalled and the top six applicants were selected. They were assigned to CSG groups based on their own expressed preferences and experiences. As I detailed in Table 3, the representatives selected by this process were highly qualified people and most had experience of working in a health or education setting. They were a mix of people with epilepsy and close family members (father/sister) of people with severe epilepsy.

Figure 11: Drawing of Interviews (reproduced from Fieldnotes)



Following on from Lucy's comments at the Management Group meeting, before the representatives took part in their first CSG meetings they attended a training day. Because of the timing of the interviews and training, the representatives were not able to participate in the second round of CSG meetings. The CSG chairs took this opportunity to explain to the other CSG members that two representatives had been appointed to the group and to give a little background on each. While discussing the terms of office for group members it was agreed that: *"that PPI representatives would serve either three-or-four year terms in the first instance, followed by three-year terms; and that recruitment would follow the same process as before"* (Extract from CSG minutes). This was congruent with the professionals' terms of office. It was also agreed that as long as the rest of the CSG had no objections any member of the group could hold consecutive terms on one CSG.

The training day was run by Ann, Lee and Lucy at Lucy's charity's headquarters. The training ran over two days with everyone arriving early evening on the first day. The evening consisted of ice breaking activities and dinner. This allowed the training day to start comparatively early; it also helped the representatives relax around each other and the professionals, thereby helping to create a relaxed atmosphere. Dinner also served as a 'thank you' to the representatives for their time. The second day included presentations on PPI, the UKERN, the epilepsy charity and an introduction to research. There were group discussions around what skills the representatives felt were needed to be an effective representative and what challenges they thought they might have. They also read a selection of lay summaries of research projects and prioritised them for funding. From the representative feedback forms and my interviews with the representatives and professionals, the overall feedback from the training day was very positive.

After the training day the representatives started attending the CSG meetings. By chance the next meeting was a face-to-face meeting. It had been decided that as most of the epilepsy community usually attends the International League Against Epilepsy (ILEA) UK branch annual conference, it made sense to have the meeting at the same time. Unfortunately this first meeting did not go as well as the CSG leads had hoped. The meetings were placed at the end of the conference by which point many of the professionals had left. Also, two of the representatives belonging to the same CSG group were unable to attend. The representatives who were in attendance met with the CSG leads in advance of the meeting to discuss their role and any requirements they had. They valued the opportunity to meet the rest of the group and introduce themselves face-to-face

before taking part in the teleconferences. However, they did feel it was a long way to travel for what turned out to be a short meeting (the longest was 30 minutes) (see Section 5.5.5). Nevertheless, after this meeting the representatives became a fixture of the CSG groups.

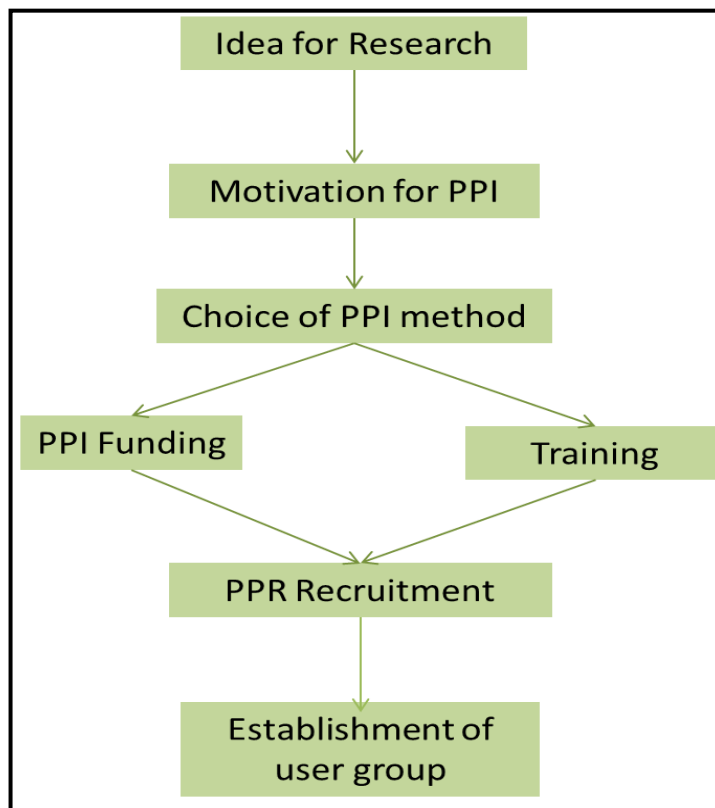
As suggested by Lucy in the original Management Group meeting, each of the representatives was supposed to be allocated a mentor from within their CSG. It was decided by the Management Group that the mentors should not be the CSG leads but rather volunteers from within the groups. This was to ensure that mentors would have time to respond to any questions their representatives had. In practice some of the representatives were not assigned mentors and those who were rarely in communicated with them. This was in part, due to how the CSG groups functioned. Representatives were in contact with different members of their CSG group beside their mentors and linked in with the other representatives. After the network had been running for two years Alex decided to hold a 'check in' meeting with the representatives to see if there were any problems or suggestions that need addressing (incidentally, this was my last observation of the network).

From my observations and the reflections of the representatives and professionals, the selection process appeared to be successful. By this I mean the representatives were active members in both the face-to-face and teleconference meetings. The experiences of the representatives and the CSG leads varied by group and are explored in the following chapters.

3.4 Child site one: intervention study

In this section I am draw upon my interviews and observations with Rachel and Nick. At the time of data collection, Nick was a Reader and Honorary Neurology Consultant. He had over ten years of PPI experience both in research and service development and was the lead researcher on the project. Rachel's formal job title was 'research assistant' but she explained that her role was closer to that of a research coordinator. She worked on multiple research projects at a time and was responsible for their organisation and execution. She had been involved in the project (developing a non-drug intervention for a specific epileptic condition) since the beginning. This was the first time that she had taken responsibility for PPI and as such she was able to give a detailed account of the entire process (see Figure 12).

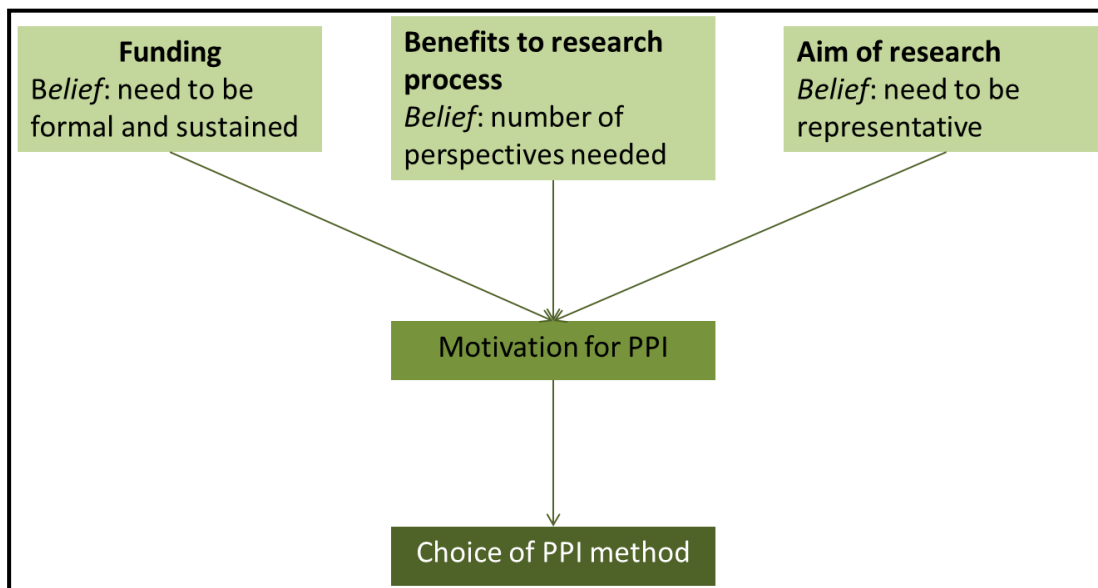
Figure 12: PPI process in child site one



When I started my observation of this group, funding had been secured for a ‘user group’ to help in the development of a research funding bid for an intervention study. The group had met on two previous occasions, involving seven core representatives, four patients and three carers. Having funding to support the group was seen as essential; Rachel felt it would not be possible to do PPI without it. Although the original research funding bid for the intervention study was not successful, by the end of the period of my data collection other potential sources of financial support for the research were being explored. The following description touches on earlier stages of the research process but focuses in depth from the point at which PPI funding had been obtained. It covers the reasoning for having a user group, how this group was recruited and how it functioned.

As illustrated in Figure 13 there appeared to be three main motivations behind the implementation of PPI in this research. Each of these motivators came with associated beliefs about how they were best addressed and the three in combination resulted in the chosen approach to PPI. I will now describe the professionals’ accounts of each of these motivations in turn.

Figure 13: Motivations for PPI



Rachel and Nick both unabashedly stated that their initial motivation to have PPI in the development of the bid was that they knew that the funding body they were targeting viewed PPI as good practice and, as such, would be more likely to think favourably of their application for research funding if it included PPI:

“I think in order to get at funding we had to set up this group so I mean really that was you know ((Laughs)) was the reason you do it because you have to sort of thing.” (Rachel)

These two individuals are among the minority of researchers who explicitly told me that this was one of their primary motivators. From the interviews and my observations it was apparent to me that they believed that PPI had to be of a certain standard in order to secure funding. In particular, they believed that it had to be in-depth and sustained. Even without this external financial motivator Nick said they would have still sought feedback from representatives. However, it would probably have been through a focus group or other less time intensive methods. For these researchers, it appears that this incentive offset the time investment needed for this form of PPI in a way that other motivators did not:

“Probably without the insistence I don't think we would have done it because it is of course an investment in terms of time ... well actually would we have done it, I think what we would have done is we would have had a focus group to go over our materials because that is kind of essential.” (Nick)

In contrast to the initial funding motivator, the other two motivators were more implicit in participants' accounts, drawing upon the understanding Rachel and Nick had of the purpose of PPI. They both believed that PPI improves research design and process, and

both motivators are linked to this. The aim of their research was to establish an education and support package for people newly diagnosed with a specific epileptic condition. Rachel believed that understanding what such people felt and experienced post-diagnosis was fundamental to developing a useful intervention, and as such, accessing representative knowledge was integral to achieving the research aim:

“Part of the study is kind of understanding what erm... patients feel like when they receive the diagnosis, when we do certain things to do them, so it just seemed really relevant and important really to include people that had been through that experience, or going through that experience as to how... how they had felt about it.” (Rachel)

As the NHS service offered to newly diagnosed patients with this condition differed widely across the UK, to truly draw upon representative experiences it was seen as important to get opinions from across the different regions: *“So definitely where you come from and what services are available, are going to affect how they think”* (Rachel). In addition to informing and potentially improving the intervention itself, Nick and Rachel believed that by making the changes suggested by representatives to the participant information sheets (that from their view were appropriate to incorporate), the research would become more ‘acceptable’ to patients, potentially increasing recruitment and reducing attrition:

“But like I said we were dependent on the comments from... our research user group, to make a study acceptable and more likely to succeed. ... we felt we could benefit from their input... I mean, yes I mean I said that, apart from fulfilling the, ticking the right boxes the main purpose was to develop this research... Despite the fact that we worked with the patients for many years and you think you know what they are like but erm... there is always, new insights.” (Nick)

Rachel also found it personally reassuring to get early feedback and validation for the project, as she believed that without representatives’ insights a project might get funding that was not worthwhile to the target group:

“You know asking for money or trying things out that just aren’t going to be worthwhile at all and I guess if you don’t ask people about that, you are never going to know are you so just from asking them straight off, ..[...].was positive for us really ((laughs))... early feedback.” (Rachel)

Nick was strongly aware of the more political and moral imperatives for PPI. He felt that these make PPI a good idea in theory. However, this alone did not seem sufficient to motivate him:

“I think, it serves a number of different purposes, erm... it erm... ensures the patient's perspective is heard erm... there is a degree of quality control, erm... it helps with accountability erm... of researchers, erm... it helps also to erm... ensure that projects are ethical, erm... [pause 10] don't know whether I have left anything

out, but there is quite a lot of reasons why erm... PPI is a good idea in principle.”
(Nick)

Given these multiple reasons for PPI in the research Nick reflected that having PPI just seemed to: *“make a lot of sense of course.”*

Once the decision had been made to implement PPI, establishing a user group was considered the most viable approach. As the purpose of PPI was to gain input from a variety of individuals, having a single representative on a working group would not achieve this:

“An obvious advantage of having a larger group is that it's slightly more representative so we wanted not only people with seizures, also wanted carers and erm... people who have responded quite well to treatment, people who have not responded and they are all in that user group.” (Nick)

The choice of a separate user group was reinforced by colleagues’ PPI experiences and Nick’s belief that having a single representative on the steering group would be ‘tokenistic’. He felt they would not be able to follow the language used during steering group meetings and as such would not be able to participate (potentially having an inhibiting effect on the rest of the group), defeating the point of having PPI. Again this illustrates how multiple motivators impacted on the chosen method of PPI. If Nick and Rachel were implementing PPI to satisfy the demands of the funding body alone, it would not matter to them if they had used what they perceived to be a tokenistic approach:

“Of course we could invite somebody into the steering group if we erm... didn't want to take it particularly seriously, ideally somebody who never says anything you know, I am sure we could select somebody like that who would come but not say anything and erm... you know we could then say we have a lay member on our steering group... but like I said we were dependent on the comments from... from our steering group, from our research user group, to make a study acceptable and more likely to succeed.” (Nick)

Their next step was to secure funding for the user group, as best practice documents outlined the need for payment and travel expenses for representatives. Around the time PPI funding was secured Rachel took responsibility for facilitating PPI in the development of the funding bid. The first thing she did was to talk to two fellow researchers: *“that have done quite a lot of work in PPI”* and attended a training day. Throughout her interview she came back to how useful the training and support had been in terms of the organisation, pitching of information and determining the content addressed by the group. Receiving training was also one of her ‘top tips’ for researchers starting to initiate PPI:

“I literally didn’t have a clue ...[.].so going to their little course they did was brilliant, because that just gave you so much information and just how to talk to people..[...].”,

it was really worthwhile going to something like that and talking to other people as well.” (Rachel)

Once she had completed the training, Frank (one of the experienced researchers) volunteered to help her establish the user group and even attended the first meeting to support Rachel and ensure the group had an optimal start:

“It was definitely it was Frank that helped me, erm... so sort of he talked me through you know how to recruit people and all this, so we sent all that out. Then we had to think about erm... we introduced like group rules, and things like that, so how we would all... what we would talk about, and that you know what we spoke about wouldn't go anywhere else, those sorts of things.” (Rachel)

When Rachel started recruitment of the representatives she prioritised the need for representatives to be representative by region and treatment experience. Moreover, they not only wanted patients as part of the group, but also carers. During my observations both Rachel and the representatives explained that they believed carers have a breadth of knowledge about the patient's condition that neither the patient nor the professionals had access to (for example, what they observed happening to the patient during and after a seizure, this was viewed as particularly pertinent for seizures associated with memory loss). Also, carers were often seen as instrumental in supporting patients through treatment. Through discussions with two local sources, a psychotherapist and charity that focused on the targeted group, Rachel identified potential representatives. She had no official criteria for those contacted; rather she made judgment calls about potential representatives known to the researchers, based on whether or not they might be able to function in a group setting:

“Maybe a screening yes. Yes. I guess erm... from some of the ones that yes, we already knew, erm... some you know we knew I mean some have quite severe social phobia, and those sorts of things so they are clearly not going to be appropriate and for you to ring them and as them, is only going to make them uncomfortable sort of thing so, but a lot of people really know, we did erm... ones we didn't know much about erm... it was quite an open invitation in the beginning really to just find willing people.” (Rachel)

The other factor Rachel was aware of during recruitment was the potentially upsetting content of the material to be discussed in the group. She never made explicit how this affected her choice of representatives, only that it did:

“For a lot who have gone through a lot of trauma or things like that, if we are then talking to them from a research basis rather than a clinical basis you have to.. you have to be wary about you know what you are asking them....so we had to be careful who we were going to invite in, but everyone seems to have erm... been fine anyway ((laughs)).” (Rachel)

Neither Rachel nor Nick felt that the representatives needed to have research knowledge themselves in order to contribute to the group. They felt that their own role was to provide the research skills and the representatives were there to give insights from their experience:

“It’s more interesting to hear from them what the barriers might be, erm... those sorts of things, than to say well I think you would get a more valid question if you asked it this way, or that sort of thing because I think that is kind of what we have got the experience in, what they have got the experience in is how we are going to be more inclusive and prevent people getting distressed or those sorts of things so.” (Rachel)

While they invited people from across the country to attend the meetings many were unable to do so because: *“obviously it’s just such a long way to travel for some of them”* (Rachel). Therefore, most of the core group members lived locally or in neighbouring cities. Two of the representatives were the carer and patient who had set up the charity that had recommended possible representatives. Having these individuals involved in the user group was seen by Nick and Rachel as a great advantage, they were seen to not only bring their own experiences but also able to draw on their interactions with members of the charity, providing an additional level of representativeness to the group:

“So they had set up a support group so they were sort of ideal candidates, straight away because they were going to have erm... a lot of experience about talking to other patients as well, erm... so they kind of brought you know a whole group of people by just inviting them really.” (Rachel)

When starting the user group Rachel followed Frank’s advice and the INVOLVE guidelines for best practice. For example, at the start of the first meeting they discussed the purpose of the group, set out group rules and covered what would happen if anyone had a seizure during a meeting. Representatives were given the option of a cash payment or vouchers (they chose cash) to reimburse their time and expenditure. Fitting with the purpose of the group, each meeting was used to look at specific components of the research design such as the intervention pack, questionnaires and participant information. The agenda and relevant documents to be discussed were determined by Rachel and Nick, with electronic and hard copies circulated in advance of the meeting. This choice of a focused and pre-set agenda was reinforced by Nick’s previous PPI experiences. Although occasionally he had received ‘useful’ information from unstructured discussions, and could provide examples of this, from his own observations he felt that: *“there are significant problems with having a free discussion with your user group about erm... research that you might want to do or that they think you ought to do”*. This is because he felt that research priorities determined by these groups were not normally scientifically grounded, that the conversation often strayed

from the topic and there were not enough tangible outputs. Both Nick and the representatives I interviewed valued having outputs at the end of each meeting. They had taken the time away from other work and family commitments and having evidence of the group's productivity helped ensure that it did not feel like it was: "*a waste of time*" (Jim, representative).

Rachel explained that initially she had set up an online discussion forum to run alongside the group: "*where they could communicate with each other and us*". However, the representatives never used it or mentioned it in my interviews with them:

"They haven't really taken that up very much. Erm... I have tried to add things on there and you know ask people to comment and things, but they haven't [38.54] no. They come to the meetings and they do what is necessary for that, but then they kind of tend to drift away." (Rachel)

Despite the fact the discussion forum was not currently being used, Rachel hoped that in the future it might be a way of getting people from different parts of the county involved, in order to increase the number of representatives providing input and thus make the group more representative: "*I think in the future we would quite like to invite a lot more people that could also discuss things on there and wouldn't always have to come for meetings*" (Rachel).

All the people I formally interviewed for this site brought up two factors that they felt had a direct impact on how the group functioned. These were the facilitator and the size of the group. During my observations I had the opportunity to see how the group functioned both with and without Nick being present; and I recorded in my fieldnotes that the mood of the room was much more stilted when he was present, with the representatives less likely to make comments. Rachel articulated this by saying: "*it all goes very quiet and formal when Nick comes in, whereas before I think we kind of just chat about everything*". This observation was also made independently by both Nick and the representatives during their interviews. This shift in atmosphere seemed to stem from Nick being seen as an expert in the field and because of his position as a Consultant Neurologist (and clinician to some of the representatives); whereas the group knew less of Rachel's background and viewed her as non-threatening. While Rachel found the lack of recognition of her own knowledge difficult she clearly saw the advantage of this in terms of getting information from the group:

"I would say that is probably quite an important thing really for them to not feel that they can't really voice their opinions because somebody who they are talking to, has

more experience than them in it,[...] ... So I think it's maybe better to have people who they view as non-threatening erm... and not as experienced as them because you will probably get better information from them. I mean I don't think Moira probably knows, I am sure well she doesn't know my background really or you know... how much work I might have done in this field so I just kind of bite my tongue you know but it doesn't bother me in the slightest, I would much prefer to have a good meeting and to get good information from her than to try and fight her ((laughs))." (Rachel)

The effect of the facilitator is an issue which I discuss in more depth in the following chapters (see Sections 4.5.4 & 5.6). It is important however to note here how the facilitator role was addressed within the meetings. The meetings were split into two parts. Nick attended the first half so that he could get a direct sense of the perceptions of the representatives and as Claire (representative) reflected, help to reinforce the feeling that the opinion of the representative was valued. During the second part of the meeting Nick deliberately left the room, leaving Rachel to facilitate the meeting, removing his 'inhibiting' presence. When I asked Nick his opinion of using a completely independent facilitator Nick refuted the idea, as he believed it would limit the functionality of the group: *"you do need somebody who knows about the research and answers their questions and somebody that doesn't inhibit the answers."*

The size of the group was the other issue consistently raised. Although other representatives attended some meetings there was a core group of four people that attended all of them. This raised questions for Rachel and Nick about the representativeness of the group. The representatives also felt that the limited group size meant that often the same points were repeated and that it would be better to get more varied views and input. While it was evident that everyone involved wished for more group members, they were less clear on what would be the optimum group size. Indeed, despite their wish for more diversity they felt that smaller groups had the advantage that each member had space to provide their input which might not happen in a larger group, particularly from the less socially gregarious members:

"I think having a smaller group can be quite useful in that they you know obviously you are not getting as many varied views, but you are I think probably getting more out of them than some of them might say if there was a lot of... a lot of people there and especially as you say that didn't know each other." (Rachel)

The representatives explained that it was not necessarily the group size in itself that influenced their level of contribution, but rather the consistency of the group membership. Having the same people present allowed them to get to know the others, increasing their confidence to contribute and to an extent, self-manage the group (see Section 5.4). Jim also

recognised that if the group continually had new members they would have to go over past information in much more depth, suggesting that given the choice, representatives would opt for a smaller, consistent, group over a larger varied one:

“Whereas if you keep the group erm, or the same people should I say coming in attendance then you will be able to progress fairly well because they will have a, a clear or should have a clear idea of right this is section 1, we are now on section 2, this is it, we will soon be on section 3, you know whereas if you get different people coming they will come in half way through, you will have to spend an hour telling them what has just been done, they will then want to give feedback into that you will then have to take that on board, to try and change the section that they are now at and it will just go to pot. ((laughs)). It will be a nightmare.” (Jim)

“I think by now people know me and know that you know I have got a few issues, and if they need to just prod me in the right direction as it were, so that I can erm, carry on saying what I was saying, rather than not remembering.” (Claire)

Along with the value placed on consistency of group membership and the motivations behind PPI, Nick felt that it was important that the group meet regularly. However, neither the researchers nor the representatives wanted to meet just ‘for the sake of it’. This and the slow moving nature of this sort of work meant that this group had reached a stagnant phase in the project towards the end of my data collection period. Nick and Rachel addressed this problem by broadening the purpose of the group, establishing them as a consultation group for the department rather than just for the project and obtaining additional funding from within the department to do so:

“Research is a fairly slow process and you know if you want their help on the ethics application then fine, then writing you know the erm... information sheets and questionnaires, or interview schedules all those sorts of things but then after that, there is not a huge lot to talk about them, so that we have kept up regular meetings, tried to keep them every sort of 6 months.... we have then asked them about other projects, erm... just because they are there anyway sort of thing and they are interested in knowing what sort of, what projects are going on at the time.” (Nick)

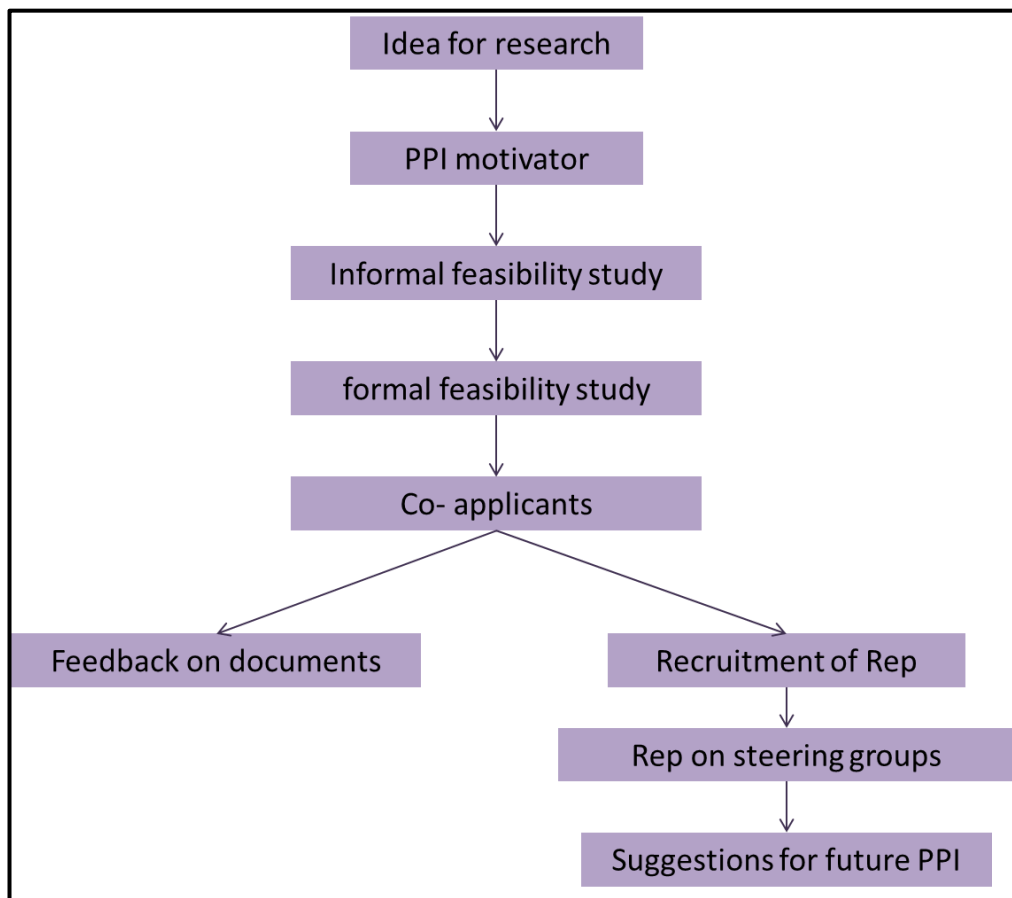
Indeed, while Rachel had no prior PPI experience before this group, she found the representative feedback so useful that she: *“now put everything past them”*. In terms of the future of the group’s involvement in the original research project, Nick was sceptical about how usefully they could be involved at the data analysis or writing up stages but could see their potential for facilitating wider dissemination.

3.5 Child site two: clinical trial

My main informants for this child site were Oliver, Bill and Sue. Oliver was a practicing Neurologist and epilepsy specialist who identified the particular research question around which the group had been established (focused on the clinical drug management of pregnant women with epilepsy) and was a co-applicant on the funding bid. Bill was a women's health specialist. He had no past experience of epilepsy research but was an experienced trialist and consequently the primary investigator. Sue, the trial co-ordinator, was brought in once funding was released. This was her first formal research post although one of her past roles had been related to epilepsy research.

From my initial conversations with Oliver about access to the trial, I had the impression that he had given little or no thought to PPI: *'I guess we are going to have to think about that [PPI]'* (Oliver, paraphrased in fieldnotes). As such, I was expecting to observe an example of a trial with minimal PPI which would make an interesting and potentially 'deviant' case of PPI relative to my other sites. I based this on my belief that the majority of researchers are not as enthusiastic or committed to PPI as the individuals responsible for shaping it in the other sites and as such they may not reflect 'typical' PPI processes. This did not turn out to be the case. There was some form of PPI at each stage of the research process; it was simply not recognised or badged as such by those involved. Figure 14 outlines the PPI process in their site up to the cessation of my data collection. I will now describe this process in more depth.

Figure 14: PPI process in child site two



The idea for this clinical trial came from Oliver and his colleagues disagreeing over an aspect of treatment for women with epilepsy. Bill then convinced them that the only way to resolve this issue was to conduct a clinical trial:

“The background to this is that erm... that service that delivered care for epileptic pregnant women in our hospital had clinicians with opposing views, so they presented those opposing views to me as part of a discussion over coffee and erm... in fact they suggested one solution could be through designing a research study and then I explained that to do such a study is not something one could do in their own clinic over a few weeks or months, and it’s going to require a big effort.” (Bill)

Once the potential need for a clinical trial had been identified clinical epilepsy specialists and women with epilepsy were approached to see if this was a question that would interest them and if they would, theoretically, be amenable to taking part:

“Right from the beginning even before the protocol was developed erm.. we requested some patients who we knew to see whether they thought this was a question worth asking. We also asked people whether they would be prepared to be randomised, erm... so yes sure we asked people whether if we embarked on such a study it would be feasible.” (Bill)

At this stage patient involvement was very informal, consisting of eliciting patient opinion through conversations at the epilepsy clinic where Oliver worked. When the response was positive, a more structured questionnaire survey was conducted, 51 patients from the same clinic completed an eight-item questionnaire. The feedback was heavily in favour of the proposed research: *“96% (n=49/51) considered the question posed in the study important needing further research and 78% (n=40/51) expressed willingness to participate in a randomised trial”* (Extract from the questionnaire summary report). This form of ‘consultative’ PPI could be seen as superficial, as representatives had no direct power in the decision making process. However, I do not believe this to be the case here as the patients’ views were a deciding influence in whether or not to pursue the research:

Beth “So if up front you were being told actually no I wouldn’t even think about doing it...

Oliver We wouldn’t have bothered with the trial yes. And that’s still a big issue if we get all this, and the patients to say they don’t want to go into it, we have got well what did we do all that for it was pointless. Erm... so that’s why it was such an important part of this, you know feasibility particularly in pregnant women.”

Both Oliver and Bill reflected on the fact that getting patient input at this stage was just an automatic thing to do, requiring no prompting for outside sources:

“For me it is natural whenever I plan a study I.. tend to ask people who will be engaged in the study in the future, whether they think it’s a question worth asking.” (Bill)

This is consistent with Bill’s perception of the purpose of PPI. Throughout his interview he alluded to different motivations for involvement but when explicitly asked he said that the point of PPI was to establish whether or not people would take part in a trial and how to facilitate this. As recruitment is a main reason cited for trial failure, it makes sense that as a trialist this was one of his primary concerns and that he valued anything that might help prevent this failure:

“Ok, to me the key purpose of patient and public participation is... to determine whether erm... [pause 04] recruitment will be feasible, and whether through their engagement it can be accelerated.” (Bill)

Alongside confirming the importance of the research question and feasibility of the trial to the investigators, patient support for the project was seen to have helped justify the research to others and was perceived to have helped facilitate the research process:

“We put it in the protocol just to back, justify the research and why it needed to be done so it was written in the start of the protocol. It has been put in the ethics application to justify the reason why the research needed to be done.” (Sue)

At the bidding and application stage there was involvement from epilepsy charities. As these charities support and represent patients and the public, drawing on group knowledge rather than individuals, it was considered by Bill to be a form of PPI. Epilepsy charities were also co-applicants on the grant. This was seen as vital by the professionals. They believed that to achieve the level of recruitment required, the epilepsy community as a whole needed to 'buy in' to the research and they intuitively thought that endorsement from the epilepsy charities would strongly influence their members' views:

Beth *"So quite a lot of involvement at the kind of charity / committee level?"*

Bill That's correct yes. That's very important in this study because it's a study that will run over 40 centres, and erm... there will be no more than a couple of patients per month recruited, so erm... the need to encourage if you like patients to ask the question to their clinicians whether or not they should be in the study is very strong in this case."

At patient level the team next asked for feedback on participant information sheets, consent forms and recruitment posters. Alongside asking an epilepsy charity for their comments, five patients selected at the epilepsy clinic were approached for feedback:

Beth *"So it was just kind of a case of you handing it them, and then going what do you think?"*

Sue Yes, I just said that this is for some research that we are planning on doing, would you mind just... this is what we are planning to give to patients so we can tell them more about the research would you mind giving me feedback and I just left them to have a look and they came and found me and just said this is what we think. Yes."

What was very evident to me here was the ease with which the investigators could access patient opinion, both through the clinic and through the research systems of the pre-existing patient networks. This was paralleled in how they recruited a representative for the steering group and data monitoring committee. Between them they gave three separate motivators for having a patient representative on these groups; firstly that it was common sense to have representatives of all stakeholders; secondly, the benefit of getting a different perspective, and thirdly that it was a requirement of the funder.

To recruit the representative the local epilepsy nurse and an epilepsy charity were asked if they knew anyone who they thought would be 'appropriate' and willing to sit on the groups. The charity put them in contact with a possible representative, who then agreed to be involved:

"Yes she e-mailed to say that she would be happy to do that, she wanted clarification first of what her role would be, erm... and what she would have to do and I gave her that information, by e-mail erm... and yes she was happy to erm... attend." (Sue)

There were no formal selection criteria for the patient representative (indeed little was known about the chosen woman). The trial team were clear however, on what they wanted from the representative and her role within the groups. In line with the earlier patient consultations, the nature of the study meant that the researchers wanted feedback from women with epilepsy and preferably from women who are, or who have been, pregnant, as opposed to partners, carers or the wider public because: *“You can only really get patient perspective, from a patient”* (Oliver).

Sue was indifferent about whether the representative had research knowledge or not, as she could: *“argue the situation both ways.”* Whereas, both Bill and Oliver felt that there was no need for the representative to have research knowledge as that component would be covered by other members of the group:

“To build a trial requires a number of different expertises, to do it and it’s the same in patients isn’t it, they have an expertise in their illness but they don’t have an expertise in trial design..[..]..., I don’t worry about the obstetric part, and wonder whether erm... whether you know, the scan at 28 weeks, what kind of scan it is, I leave that to the obstetricians you know and they are competent, erm... and I leave it to them. I am not worried about it, and I am worried about the epilepsy side of things and that part of the trial.[...]. you know I don’t understand it all but I can still be involved with it..[..]... It’s the same with the patient I don’t think they need to know everything about the trial, but they need to know what affects the participants.” (Oliver)

Building on this, Oliver felt that representatives having a research or medical background could be detrimental to getting a ‘true’ patient perspective. He not only valued the opportunity to get the perspective of someone with epilepsy but someone who did not have a ‘medicalised’ view of the world:

“So the benefit would be then they may think of problems you haven’t thought of as a clinician which ...[...]., you know they are thinking from a patient perspective because we are thinking about what data we collect, blood levels they would be thinking God all these forms that’s ridiculous...[...]. so thinking of novel problems that we haven’t thought of.[...]. because we have all be trained to think the same way.” (Oliver)

During my data collection at other sites it was repeatedly raised that having one representative on a committee is likely to be tokenistic (see Nick’s comments in child site one). When I put this to Bill he was of the opinion that it is only tokenistic if you do not listen to them:

“If you invite people to contribute then you have to first of all give them a chance to say what they are saying, then you have to have an appropriate response, it’s not necessary that what every individual contributes has to be implemented but it has to be heard ((laughs)).” (Bill)

At the end of my data collection, Ethics Committee approval had just been received for the trial. While my informants had no concrete plans for additional PPI, they commented that if the trial failed to recruit they would consult with patients to find out why women were not joining the trial and identify how to address this. However, as there was a qualitative research study attached to the trial it was likely this information would be obtained through participants, rather than via independent representatives. There was also the presumption from the professionals that epilepsy charities would help with the recruitment and dissemination stages of the research processes.

Consistent throughout the interviews with Oliver and Bill was the view that they did not see PPI as something separate from the research process. They took the line that talking to patients was what they did as doctors and that it was '*good research*' to seek out, respond to and incorporate patients' perceptions, just like that of any other stakeholder (e.g. statistician, trialist and obstetrician). In addition, it became evident that Oliver was uncertain about the specifics of PPI terminology:

Beth What is your current understanding of what patient, public involvement is?

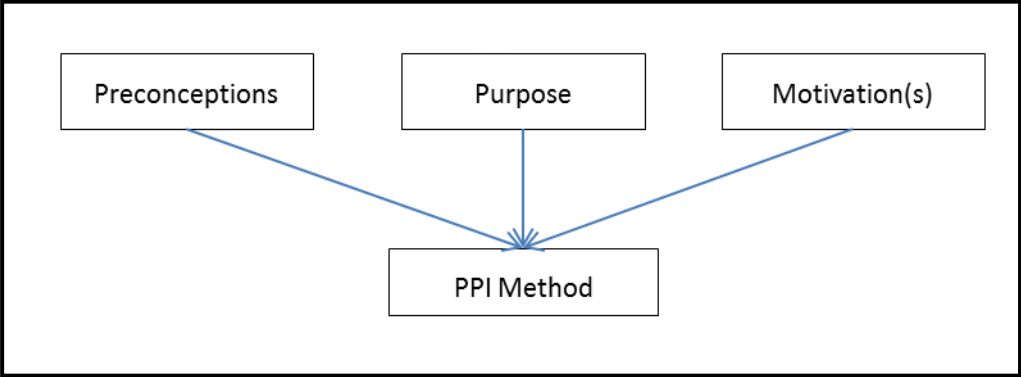
Oliver I don't... the answer is I don't know. Ok. Because it sounds like it means a specific thing and I am aware of them you know that we have got somebody a member of the public on the trial steering committee, and I remember that we involved patients in terms of the trial design, in terms of the feasibility would they be involved, you know real women that were pregnant would they consider a trial and they said yes, the majority have said yes. I understand that kind of involvement but I don't know what that quite means in these terms.

This may be why, initially, it was difficult for them to identify PPI in their project, as they did not set out to have PPI in their trial or classify it as such, they sort to gather information from all stakeholders as appropriate.

3.6 Discussion

In this chapter I have explored the different processes and approaches that the each site used in implementing PPI. Consistent across all four sites were three factors that influenced the PPI approach used: the initial motivation(s) for PPI, the perceived purpose of PPI and the preconceptions of what 'involvement' means (see figure 15).

Figure 15: Influencing factors



Preconceptions about what constitutes ‘meaningful’ involvement and what constitutes ‘tokenistic’ involvement were clearly evident throughout the sites. The professionals in the intervention study did not consider having representatives on their steering group as they thought this would be ‘tokenistic’, believing the representatives would struggle to contribute. In contrast, the professionals in the clinical trial felt that as long as the representatives were listened to, then having them present at their steering group and data monitoring committees meant that they had meaningful PPI. The comparator epilepsy network felt that representatives would not contribute if they were part of the main research development group and as such this type of involvement would be tokenistic. In contrast the UKERN believed that keeping the representatives separate from the professionals would result in them having no direct impact on the priorities and functioning of the network and as such they would not truly be involved. All of these views seem to be underlined by the same belief that for representatives to be involved in research they need to be given the opportunity to voice their opinions and have them taken into consideration. This fits with, and builds on, the perception in the literature that regardless of the method of involvement a key component is that there is an active, genuine partnership between the researchers and the representatives (Boote, Barber, & Cooper, 2006; Caron-Flinterman, Broerse, & Bunders, 2005; Rhodes et al., 2002; Williamson, 2001). What varied is what was and was not determined to be a ‘valid opportunity’. Another influential preconception was the professionals’ beliefs about representatives’ capabilities. These views helped to determine how representatives were selected, which in turn seemed to influence other aspects of PPI such as whether or not representative were included in meetings of the research teams, decisions around inclusivity and perceptions of what is tokenistic involvement.

The motivation(s) for and perceived purpose of PPI overlapped heavily within and between the sites but, as demonstrated in the intervention study, they were not necessarily the same. While a range of motivators for PPI were given by the professionals, such as increasing the chance of obtaining funding or because it is ethically right to do so, the sustaining motivator seemed to be the professionals' underlying belief that the purpose of PPI is to improve the research process and in turn having PPI is 'just good research'. The ways in which they expected PPI could improve the research process directly impacted on their approach to PPI. For example, if professionals thought representatives could only be helpful in initial stages they would not include them in data analysis and dissemination. Whether or not the professionals believed PPI needed to be broadly representative of everyone within the epilepsy community, or that representatives were there solely to reflect their own experiences impacted upon the number of representatives included in each model. During my observations the effect of funding on motivation was repeatedly alluded to. This was not in terms of obtaining it but rather that when research is a publicly funded enterprise, as with the UKERN, the moral and ethical arguments for PPI have a greater importance than in privately funded situations. Having detailed the process of PPI the following chapter explores the professionals' experience and perceptions of undertaking PPI in more depth.

Chapter 4. Professionals' experiences and perceptions of PPI

4.1 Introduction

In Chapter 3, when discussing the site-specific motivations and decision-making processes around PPI, the professionals' perspectives were paramount as they had access to aspects of the PPI process that the representatives were not involved in. As such, I have already started to address the first half of the third research objective: *'to describe the experiences of the people involved in the PPI process, including their perceptions of the benefits and challenges of PPI'*. In this chapter, I will build on this and also address the remainder of the objective by exploring the professionals' perceptions and experiences of PPI more broadly. Where appropriate I will then start to: *'compare and contrast the theoretical underpinnings of PPI with its practical application'* (Objective 2). In Chapter 3 I compartmentalised information from four of the study sites in order to convey the individual PPI stories as case studies. In this chapter I will draw upon all of my 'professional' data across the main, sibling and child sites. As described in Chapter 2, this consists of 25 interviews with 21 professionals, fieldnotes from observations and two key documents¹⁰. I will first describe how the professionals experienced and understood PPI, then their perceptions of its main benefits and challenges.

4.2 PPI as an emotive topic

Whatever else the professionals' experience of PPI might have been, it was rarely a passive one. Whether as part of my formal data collection or when discussing my PhD in passing at my own departmental coffee morning, it was clear that everyone had an opinion on its value. I was presented with many examples of polarised views both for and against PPI. There were those that felt it should happen at every stage of the research process and conversely, those who felt it should not happen at all. It should be noted that those in favour tended to be more vocal. This may reflect the moral discourse that permeates PPI (see Section 1.5.1) and the current Department of Health stance (see Section 1.5.3) on PPI

¹⁰ 'The Way Forward Report' and the 'Making a Difference Report' - both of which were generated by the NIHR Clinical Research Network internal evaluation of PPI.

which may make it seem ill-advised to express the view that PPI is a waste of time. The strong feelings around PPI were something that Fred (NL¹¹) described:

“I am sure you will find that, there are people who have very strong opinions one way or another. You will get professors, although you probably won't get to talk to them, but you will get professors who secretly think it's all a complete waste of time, and completely illogical, erm... and then you will people who erm... are kind of like very strong militant campaigners for PPI as if erm... you could never have too much erm... and (laughs) yes strong feelings.”

Between these extreme positions lay the majority of professionals, who seemed to be of the opinion that PPI is essentially a good thing and should happen. They were however ‘sceptical’ about how much impact PPI actually has on research: *“just the sheer scepticism on both sides actually, on the part of researchers that, can patients can make a difference, a positive difference to their research”* (Charlie, NL). Professionals who had multiple experiences of PPI seemed to easily recall both good and bad experiences, but believed that overall PPI: *“tends to be positive and beneficial”* (Nick, CP¹²). In line with this, the majority of my key informants can be described as having a mostly positive, but somewhat sceptical, attitude to PPI. There also seemed to be a large group of academics who valued PPI but were glad that it is someone else’s job to facilitate it:

“I think, generally people think of it as a good thing [the patient group], you know, you know, you couldn’t knock it erm, And I think lots of people are pleased that other people are running it, you know, that it happens, they don’t have to invest so much time into it, and if they wanted to access it, it would be there.” (Tom, CP)

4.3 Professionals’ understanding of PPI

In my initial interviews I asked the question ‘what is PPI?’ This tended to elicit fairly similar answers and while the question was an ‘open’ one, the answers seemed ‘closed’ or superficial, leaving little or no room for exploration. Around the third interview I realised asking the question ‘what is the purpose of PPI?’ resulted in a more personalised, open and revealing responses.

4.3.1 What is PPI?

The answers professionals gave to the question ‘what is PPI?’ were largely variations on the idea that PPI is ‘about involving people in research.’ This was most neatly articulated by Francis (CP): *“It’s what it says it is. It is about involving non-professionals, so involving public and patients, so patients and carers and people who have got a personal experience of*

¹¹ NL= Network PPI Lead

¹² CP= Clinical Practitioner

epilepsy rather than necessarily a professional one". Only one professional drew upon the different theoretical categorisations of PPI discussed in Chapter 1 ((e.g. Consultation, Collaboration and Consumer controlled, (Boote, Telford, & Cooper, 2002)). When describing what PPI is, the majority gave a range of examples of types of PPI that they were aware of, such as representatives on steering groups and PPI in the development of patient information and study design:

"It's patient and public involvement in research process. And of course it can happen at all stages of research, in the generation of research ideas, in the formulation of research projects ... in the erm... [pause 05] preparation of materials like information sheets, consent forms, in the recruitment of patients. In the analysis of data sometimes, in the communication of findings ... also patients, public are now involved in the regulation of and supervision of research so if you apply to funding bodies then they will have patient, public representation on the grant award committees, there will be, patient, public involvement in the ethics application process." (Nick, CP)

As demonstrated in Chapter 3, professionals placed importance on 'meaningful' or 'real' Involvement, emphasising that representatives needed valid opportunities to express their views. This was intrinsically linked with their understanding of 'tokenistic' PPI which is addressed in section 4.5.2.

4.3.2 What is the Purpose of PPI?

In Chapter 3 I also highlighted how the professionals across the sites had different motivations and goals for incorporating PPI in their own research. However, professionals were consistent about the generic purpose of PPI. Nearly all either explicitly stated or alluded to the idea that the purpose of PPI is too ensure that research is 'relevant'. For example: *"It's to try and make sure that the research is relevant to patients and the public,"* (Alex, ND¹³) and: *"it's a means to root what we do in a way that is relevant to people that have the condition that we are studying"* (David, CP). 'Relevant' research equated to 'beneficial' research that would be useful to the public, which for these professionals was a key aim of conducting research:

"The main goal, of patient and public involvement in research and all our activity is to produce and deliver research that is to the benefit of patients...[..].So that is the outcome that I would want to see. It is effective research, quality and effective research that is shared to the benefit of patients. That the research is implemented into care, and treatment." (Lyn, NL)

"The research focus shifted erm, if it's required shifted a little towards the patient benefit, what actually patients are going get out of it, at the end of day, what sort of

¹³ ND= Network Director

care might be influenced, erm by having a, perhaps the research question changed slightly or maybe even the approach to, to possible participants changed slightly.” (Owen, NL)

“I guess at the end of the day what we are trying to do is improve the quality of life of patients through research and surely they should have a say in how that is done and organised.” (Alex, CP & ND)

This suggests that although increased ‘relevance’ is one of the most commonly listed perceived benefits of PPI in the literature (see Section 1.6.1), for these professionals it is not just one of many benefits, it is the primary function of PPI. This was seen as particularly important because some of the professionals thought researchers have a predisposition towards pursuing a topic because they find it inherently interesting or because funding is currently available, rather than because it is potentially beneficial. This type of research was referred to as ‘navel- gazing’ or ‘having a hobby horse’. Professionals also suggested that a researcher could be pursuing a topic that they thought was useful, but in practice, the topic is unlikely to be ‘important’ to patients. They believed that PPI could help reduce the likelihood of such a situation arising, in turn increasing the relevance of research:

“There are certain kinds of research projects I have seen where I think it is a little self-serving, it is because it will produce papers, it’s because erm... it will bring in grant money, prestige, other factors there are these things to consider.” (Charlie, NL)

“I don’t know if you were in the research session here this morning, but it was about experimental epilepsy and it was about studying epilepsy models that conceivably have no relevance at all to the experience of people with epilepsy. Erm, and I think it’s very easy as a researcher, to get interested in what you do, and interested in what your peers are doing but to have no focus whatsoever on how this translates into patient benefit. And, I think it’s also very easy to assume that we know what patient benefit is, when actually most of us in epilepsy research don’t have epilepsy. So I think that grounding what we do, rooting what we do, in terms of a clear and knowledgeable focus on what will be to the benefit of the people with epilepsy is essential, and certainly for me that’s where PPI involvement becomes crucial.” (David, CP)

“The hope being that that would, you know, increase the chances of you answering questions that mattered to patients. That you come to some sort of agreement between what the doctor thinks is important and what the researcher thinks is important with what the patients think is important because they are often not the same.” (Francis, CP)

This supposition is supported by Boote et al’s (2012) reflective case study on how PPI led to researchers abandoning a proposal based on representatives’ feedback, even though it had received positive interest from other professionals. Some of the professionals also highlighted that PPI is likely to be most effective in ensuring relevance if it occurs during the prioritisation and design stages of the research process:

“By having involvement at the very beginning of this trial design, not just when it comes to designing the patient information leaflets, then you know there is more chance of it being relevant to the public and you know, so that’s I think that’s the ultimate goal.” (Adele, NL)

In addition to increasing relevance of research, some of the professionals thought that the purpose of PPI was to improve the research process by drawing on different points of view and experiences. These issues were covered in more depth when I asked professionals about the broader perceived benefits of PPI. Therefore, in line with how the professionals framed these issues, I explore them in more detail in 4.4.

4.4 What are the benefits of PPI?

In my review of the literature I concluded that there is very limited evidence about the positive or negative effects of PPI on professionals. This gap in evidence might be partially explained because the benefits to the researcher (the main subset of professionals) and benefits to the research process were viewed fundamentally as one and the same by professional informants. Since much of their professional identity was linked to the research process, anything that benefited the research was also perceived as directly or indirectly benefiting them.

4.4.1 Increasing relevance

Given that most of the professionals perceived increasing the ‘relevance’ of the research to patients as the primary purpose of PPI, it is not surprising that this emerged strongly as an apparent benefit. What is interesting here is how the professionals saw PPI impacting on them personally and, in turn, the relevance of the research. They felt that PPI helps: “reminds us why we are here” (Sara, NL) and: “I suppose it brings them [researchers] back to reality” (Adele, NL). Alongside increasing motivation for their work, PPI was seen as bringing the need to be ‘outcome’ or ‘patient’ focused to the forefront, the logic being that if patient benefit is an aim of the researcher it will be translated into the research process, increasing the likelihood that research and its outputs are relevant. This would especially be the case where representatives were helping to confirm what is and what is not relevant:

“Going back to my initial point of patient-centric research, you know it reminds you about why, why you know people do their 12/14 hour days, you know why people do go the extra mile when they have to write grants and, erm, papers, and it is, you know it is really about urm, you know a difficult, chronic, community based-condition, which needs far more multi-disciplinary approaches.” (Lee, CP)

“I think the group erm reminds us of what we are doing and who we are doing it for, not everybody in the group has the opportunity to go to epilepsy clinics, meet people with epilepsy face to face.” (Tom, CP)

In addition, having representatives’ confirmation that they considered the research to be ‘relevant’ was reassuring to some professionals. This reassurance could help increase their own confidence in the research question and could also be used when justifying the research to others:

“We were able to feel confident that we were asking questions and trying to answer them in a way that was relevant to patients.” (Alex, CP & ND)

“Just to hear that people are happy with what we are planning really, you know when we ask them about... [..].to hear from them straight away what they would think about receiving this sort of thing erm... and to hear from them that they thought that it was a positive, ... [..]., I went down to give a presentation the other night and someone asked me a question. And I said well funny you should say that because our, you know research user group, said....” (Rachel, RC¹⁴)

4.4.2 Gaining funding and ethics approval

Although, superficially, funding and ethics are two different elements of the research process, the professionals believed that PPI has four potential ways of influencing both of these elements. Firstly, when submitting an application to either an ethics or funding panel it is likely that applicants will be asked whether they have involved or intend to involve representatives. A positive response was seen as potentially increasing the likelihood of gaining ethical approval or funding: *“From a rather slightly flippant administrative point of view it means you, you have ticked that box on the application forms”* (Alex, ND).

Secondly, many ethics and funding panels have patient or public representatives as members. Having PPI in place prior to a panel’s review of the funding application was seen by some as pre-emptive, in the sense that it helped to address any potential issues about the research that the representatives on the panel might have. This may reduce the chance that an application would have to be resubmitted based on the representatives’ comments:

“The funders are using erm, their patient groups to, to comment on what might be a, an interesting study, something they might be interesting in taking part in. So I think it sort of closes the loop a little bit really, that the patients are commenting on that, as lay members do on ethics committees too. Actually having the patient early just solves problems that may come along later.” (Owen, NL)

Thirdly, PPI was seen as providing evidence to the panels that the research was ethical or relevant:

¹⁴ RC= Research Coordinator

“It’s that word of mouth that perhaps actually getting patient input early seems to work. Erm, I think it does, I think sometimes the erm, the applications that go in will say we have talked to, to some patient groups within the network or outside of the network and discussed this with, with them before, or during, the er sort of preparation for the proposal and that, that seemed to carry some weight especially with, erm, with lay reviewers.” (Owen, NL)

Fourthly, and arguably most importantly, some of the professionals expressed the belief that PPI does actually make research designs more ethical and more relevant and, as such, more likely to be successful at the funding and ethical approval stages:

“There has been a few cases where the parents especially have said, actually you know this, is unethical to do this research as it stands, as it’s designed like this and you know, and suggested ways to make it ethical.” (Adele, NL)

Alongside the professionals’ wishes to undertake relevant and ethical research was the more pragmatic acknowledgment that research is a slow process and anything that can expedite it was considered advantageous, or as noted by Charlie (NL): *“things getting through Ethics Committees quicker will please researchers.”* Professionals’ perceptions about how PPI can impact on the ethical aspects of research overlap with those identified by INVOLVE. INVOLVE’s (2012d) review of ethical aspects of PPI in three literature reviews identified five ways in which PPI can potentially make research more ethical: i) making research more relevant, ii) helping to define what is ethically acceptable, iii) improving the process of informed consent, iv) improving the experience of participating in research, v) enhancing the dissemination of research both to the participants and the wider public.

4.4.3 Increasing recruitment and retention

When discussing the potential positive impacts of PPI, the professionals identified a variety of different benefits to the research process, including access to ‘a different perspective’, better communication and increased networking and dissemination. These were linked by the belief that improving these areas of the research process would improve recruitment and retention of participants to research studies.

The professionals strongly valued PPI as an opportunity to ‘get a different perspective’. They believed that representatives’ perspectives were grounded in their personal experiences of being ill and receiving treatment (or caring for those that have been ill). These experiences were seen to give representatives important and unique knowledge only available to those ‘within’ the condition. Consequently having PPI was seen as a way for professionals to draw on information that they could not access through any other means:

“That although I am cynical about PPI, what they [representatives] will provide is a unique and interesting perspective because that perspective will come from something that none of us possess and that is the experience of being ill with that particular condition, with epilepsy.. and that is a unique perspective.” (Lee, CP)

“The benefits of having that patient perspective is so valuable because they bring a different perspective to the table, and very often things that your agenda is not even addressing, you are not even thinking about it.” (Fred, NL)

Within the literature this type of embodied knowledge is sometimes referred to as ‘experiential knowledge’ (Caron-Flinterman, Broerse, & Bunders, 2005). It is this experiential knowledge that representatives use to make judgment calls about the relevance and practicalities of a research aim and design. The validity of making research decisions based on experiential knowledge, which by its nature is subjective, has been debated in the literature (Caron-Flinterman, Broerse, & Bunders, 2005; Popay & Williams, 1996). It is clear however, that professionals in the present study thought such experiential knowledge could help improve the research process and, in turn, believed that improving the relevance and design of research would result in higher participation and retention rates:

“Things that can seem small, like taking a certain question out of a questionnaire, all those sorts of things, just erm... You know research is difficult enough and particularly in these sorts of patient groups, and so, anything you can get really that is going to be a potential barrier and is going to mean that you lose people along the way, if they pick up on those straight away and we can take them out you know before we even start the research, then potentially really beneficial.” (Rachel, RC)

“If trials are well designed then they are more likely to retain, you know, the patients in the trials as well.” (Adele, NL)

One of the most common forms of PPI is obtaining feedback on recruitment materials such as participant information sheets, the intention being that if participants can better understand the research being presented to them and see why it is relevant, they will be more likely to participate:

“So that if somebody is approached about it, that they can actually see the benefits that that research may give to the wider public. Erm which sometimes is not always obvious for the general public and for those being approached, I think sometimes they will look at certain studies and just think, “well what the hell has this got to do with me?”, where I think some good patient / public involvement early on could actually make it far more obvious to participants so I think that helps on the recruitment side.” (Owen, NL)

Some of the professionals felt that PPI could help improve verbal as well as written communication. They openly acknowledged that communication between academics and the general public in the research process can be far from ideal: *“I think up to now the*

research community has been relatively poor in erm, in really communicating with the general public” (Owen, NL). By interacting with representatives who have a remit to say when something is unclear professionals saw PPI as giving them an opportunity to have their assumptions about what is common knowledge challenged and could adapt how they communicate accordingly:

“I have to sort of kind of think, oh hang on I had better not use that jargon, and I think that’s, that is a good thing, I think that can only be a good thing if we start discussing research in ways that are understandable to non-academics. I hope they [representatives] will just sort of, facilitate that. ..[.].There are times that I think they have struggled a bit with the language. I think that actually is good for us because it makes us as I say, re-explain things, or clarify or you know things that seem obvious to you as a professional who has been working in epilepsy for 20 years, then sometimes it does need someone else to kind of go “sorry I have absolutely no idea what you are talking about” ((laughs)) for you know to realise you are making assumptions about people's knowledge.” (Francis, CP).

If somebody says OK we need to be looking at voltage-gated potassium channels in Rasmussen’s syndrome, you know I think I need to translate erm, and hopefully other members of the committee will start to [02] maybe communicate a little bit more clearly, and in a way that a lay person would be able to erm, helpfully understand and engage and contribute.” (David, CP)

Lastly, the professionals acknowledged how useful PPI could be in the dissemination of information about the research. While a couple of researchers speculated that representatives might be useful in disseminating the findings of individual projects, most focused on the representatives’ abilities to raise awareness of specific research projects or the research network as a whole through their social networks. There was always the chance that a representative interacting with their peers might mention a research project to an eligible friend who was not aware of the research. On a larger scale, a representative might also take part in other research projects or belong to charity groups, hence allowing access to a larger group of potential participants (e.g. through a website) or interested colleagues:

“Another benefit is those lay people can sometimes act, they will sometimes mention the network when they are wearing other hats, so if they are patient, public involvement person in the network they might also happen to sit on their local erm... PCT or whatever they are calling them in the future erm.. Patient board or that, and they might raise research issues there.” (Fred, NL)

“Here are some very concrete benefits, such as improved recruitment into studies, erm, so for example where we have collaborated with erm epilepsy voluntary sector organisations, they have then publicised the research to their membership er and that has given us access to a whole new pool of research participants, that we wouldn’t necessarily have seen through our clinics.” (David, CP)

As previously noted, failure to recruit is reported as a primary reason for non-completion of clinical trials (McDonald et al., 2006; Watson & Torgerson, 2006). Non-completion of research can be detrimental to researchers' careers and PPI was sometimes valued for these potential and varied ways it might prevent this from happening.

4.5 What are the challenges of PPI?

My analysis of the data identified six main aspects of PPI that that the professionals reported finding challenging or difficult. I have categorised these challenges as: *those* representatives, the problem of tokenism, time issues, blurring of roles, disruption of academic norms and worrying about getting it right. It is worth noting here, that in my literature review I found few references on the challenges PPI posed to professionals, with the only concerns mentioned being the blurring of roles (Faulkner & Thomas, 2002) and issues of representativeness (Entwistle, Renfrew, Yearley, Forrester, & Lamont, 1998; Entwistle, Sowden, & Watt, 1998; Rhodes et al., 2002; Lindenmeyer, Hearnshaw, Sturt, Ormerod, & Aitchison, 2007).

4.5.1 'Those' representatives

Without exception, every professional I encountered had at least one story about the difficulties of 'one of *those* representatives'. The professionals held a shared understanding of what one of '*those*' representatives' meant, referring to them in conversation the same way as one might use a cultural idiom. Common traits of '*those*' representatives as identified by the professionals included: "*having an axe to grind*", "*have an agenda*", "*troublesome*", "*aggressive*", "*argumentative*", "*self-centred*", "*hobby horsing*", "*destructive*", "*angry*", "*looking for a soap box*" and "*harping on a single issue*".

The fundamental problem that the professionals expressed themselves as having with 'one of *those* representatives' was that they believed the person concerned was not involved in the research to contribute to it, but rather, solely for their own purposes, for example, trying to get better care or to having an opportunity to express their anger about their condition and its impacts:

"When you have people who are basically angry about the services that they are getting. And use it as a kind of, use their involvement as kind of soap box to voice their dissatisfaction with services rather than what they are there to do which is to help with the research at hand or they just, they are just angry people. They are just destructive." (Charlie, NL)

“There have, on occasions, been individuals who have become involved who clearly have an axe to grind and that it’s not actually about contributing to the development of research or to research strategy but it’s about you know, a specific issue that affected this specific person for which they want some kind of specific outcome.” (David, CP)

“I want to know whether they are there because of, because they are really interested in research, or they are there because there is a political agenda that they want to meet or address.” (Lee, CP)

To compound the issue, ‘those’ representatives ‘grinding their axe’ were often perceived to do so in a way that was not socially acceptable to the professionals, being seen as verbally (or in some cases physically) aggressive or rude. The point was raised that were a fellow professional to act in such a way, there would be ways to address their behaviour. However, due to the uncertainty of roles (see Section 4.5.4) and the wish not to upset the representative (see Section 4.5.6) the professionals often felt that they had no acceptable recourse in such a situation:

“Because it’s a research team it’s not a, they are not under our control. ...I think that is a problem. That almost anything is accepted, you know, aside from someone actually physically attacking someone erm.. there is too much acceptance of bad behaviour.I think there is a fear of upsetting people.. people tend to sort of say but I am ill, you know that’s why I was swearing or that’s why I was behaving this way. They cover themselves in the patient cloak dishonestly so in the majority of... sometimes it’s true though sometimes they are ill. Most of the time I think it’s used as an excuse.” (Charlie, NL)

“They were almost, you know, fighting who could speak loudest and first, and it was very difficult to erm... sort of take the lead role and to say ok, that’s really important, but now can we ask somebody else to speak.” (Rachel, RC)

“That is quite difficult and needs some very sensitive handling. You know there may be people who feel that they are very generously giving their time, but actually from the perspective even of other PPI individuals, they are bringing a problem rather than some kind of benefit.” (David, CP)

It appeared that where a professional’s first or only experience of PPI was with one of ‘those’ representatives, the experience instantly made them dubious about the value of PPI and considerably less likely to see themselves engaging with PPI in the future:

“Health care professionals think, well patient public involvement doesn’t work, this is what you get from it, you get one patient, who goes on about the same thing every time we meet. ...[..].So that sort of thing can alienate people from, from actually getting involved in patient public involvement and I have seen it on a couple of occasions with a couple of researchers who are quite senior, erm, but have just seen one bad experience and, and are now erm almost sort of set against us in engaging and involving people.” (Owen, NL)

The professionals were quick to point out that the majority of representatives were not like ‘those’ representatives: *“In my experience vastly, vastly more people are willing to listen,*

willing to argue their case in a very sort of open and fair way, than there are people that have axes to grind. It's 100:1 but it's just the odd one that can actually set people on edge" (Owen, NL). They also freely acknowledged that some professionals were also axe grinders. However: *"it fosters a kind of cynicism on everyone's part which I think is unhelpful"* (Charlie, NL) and while: *"I wouldn't want to overplay this as a problem, it is something that is a very real phenomenon"* (David, CP).

4.5.2 'Tokenism' as a dirty word

One topic that was repeatedly raised was that of tokenism, with professionals highlighting that: *'you must not be tokenistic', 'I would not do that, it would be tokenistic', 'I did not like the way they did that it was very tokenistic'*. Tokenistic PPI from the professionals' point of view was seen as doing the *'bare minimum'*. This often consisted of having a person present so that it could be said that PPI had happened, even though professionals had not wanted, been able to, or allowed representatives to contribute in a 'meaningful' way. Examples cited of tokenistic PPI included not providing the information representatives needed in order to contribute meaningfully, using jargon so they don't understand what is being discussed and using a representative known to the professionals rather than someone that is 'appropriate' for the research in question. This type of PPI was also referred to as *'lip service'* or *'tick box'*, and in one case as *'window dressing'*:

"To fulfil the requirement with the minimum effort erm... necessary and without making any effort to actually integrate this person. Of course we could invite somebody into the steering group if we erm... didn't want to take it particularly seriously, ideally somebody who never says anything you know, I am sure we could select somebody like that who would come but not say anything and erm... you know we could then say we have a lay member on our steering group." (Nick, CP)

"Well I guess it's [not being tokenistic] making sure that people aren't just sat round a table for the sake of it, erm, that if they are round a table they know why they are there, along with the other members, erm, and that they have a clear remit, purpose, for being there, and that any feedback or input they give, erm, is they are given support to, to bring that to the table. ..[...]... making sure that, you know, people do contribute, meaningfully, that it does have in some way an impact or influences the debate or discussion or the quality of the discussion ...[...]... people were being set up to fail, because there weren't the structures and processes to actually enable them to get on and do a piece of work properly and that some of the activities were perhaps a bit more tokenistic ..[...].. I think also putting, involving people in things where decisions have already been made about particular pieces of work you know, erm if there realistically is no opportunity for people to influence or change." (Sarah, NL)

There seemed to be a general consensus among professionals that PPI is often tokenistic and that engaging in tokenistic PPI either unintentionally or intentionally was

reprehensible. It appeared that many of the professionals felt that it would be better to have no PPI at all than to have tokenistic involvement. The issue of tokenism was also raised as an area of concern in 'The Way Forward Report' a PPI evaluation report generated by the NIHR Clinical Research Networks: "*concerns were expressed around certain pockets of tokenism and some of the inappropriateness of such involvement e.g. putting someone on a committee for the sake of ticking a box*" (p. 2), offering further evidence that it is area of importance to professionals. Like PPI itself, professionals had strong opinions about tokenistic PPI indeed, they often seemed to consider it as an abhorrent thing to do: '*being tokenistic is wrong, when I watched it happen at a meeting it disgusted me*' (fieldnotes: a researcher who was not directly linked to one of the sites but who was present at an observation during a conference). They placed great importance on not being, or not being seen as, being tokenistic, as they saw being tokenistic as culturally or morally (and in most cases personally) unacceptable.

As the issue of tokenism was repeatedly raised by the professionals, in later interviews I asked them to explain their understanding of what tokenism is (as described above). Though they were happy to explain *what* they thought was tokenistic PPI none of them explained *why* they saw tokenistic PPI as being unacceptable. As is the case for many culturally accepted norms, articulating exactly why something is acceptable or unacceptable can be difficult or seen as unnecessary. Coinciding with this, the professionals' beliefs and concerns about the prevalence and significance of tokenistic involvement are not reflected in the current literature. During data collection, I anticipated that because tokenism was such an important issue to professionals that it must be heavily addressed in the literature. On investigation I realised that it had not come out in my review of the literature and on further investigation I was only able to find passing reference to tokenism in a few papers, normally in relation to types of PPI and with no explanation about its meaning (Arnstein, 1969; Dewar, 2005; Thompson et al., 2009). Rather than being based on the literature, it appeared that the professionals' perception of the prevalence of tokenistic PPI came from their own experiences, for example, having sat on management, steering or ethics committees that involved representatives who were treated in what they perceived to be a tokenistic manner. The representatives also had strong opinions about what is and is not tokenistic PPI, providing examples of what they viewed as tokenistic and what they viewed as 'meaningful' (see Section 5.2.2).

One approach that some of the professionals identified to avoid tokenistic PPI and to ensure ‘meaningful’ involvement was to be strategic or pragmatic. They describe this as involving representatives when they could have the most ‘perceived’ impact on the research process, rather than having potentially tokenistic involvement at all stages ‘for the sake of it’:

“We have to think in each case is this going to add value to the whole of the meeting. What is on the agenda, how can PPI influence the agenda, can it influence the agenda, is there appropriate erm, is there agenda items that actually could be dealt with outside of the meeting and fed back into the meeting. So those, those, erm, really questions because of resources we have got to be erm, show added value that now we have to be a little bit more innovative about the way we embed PPI in our work...[...it’s how with limited resources do we embed PPI and again I think, it is a challenge but it’s an opportunity because erm, it makes, especially with the Way Forward [report] one of the recommendations is to be more targeted, to come together and actually do things together, instead of it things going on in different networks because what we have recognised is there is lots of good practice out there, but there might be a bit of duplication.. more about now moving towards coordinating activity, doing erm, developing activity together so that, that eliminates it, so that is a better use of resource.” (Lyn, NL)

This was also seen as a way to manage limited time and resources: *“because the resource limits we have, there are things we would like to do but you just have to be, what is achievable really within the resources and be honest with people (Sarah, NL).”* This position does not fit easily with the government recommendations to have PPI in all stages of the research process and the hierarchical models of PPI offered in the literature (see Sections 1.4.1 & 1.5.3).

Focusing on PPI quality rather than quantity makes sense in light of the benefits and challenges professionals reported experiencing as part of the process. This type of PPI could, of course, be dependent on the professionals own (self-proclaimed) ‘sceptical’ view of PPI. As such, if they were unsure whether or not PPI could have an impact on their research, they might chose not to include it to avoid ‘tokenism’. In addition at this level, preventing tokenism could be used as an acceptable moral argument against facilitating PPI. This is particularly pertinent in the value-led culture of PPI.

4.5.3 Is it worth the time?

A recurring challenge or barrier raised by the professionals was the amount of time meaningful, non-tokenistic PPI took out of their working day. Professionals pointed to the additional practical difficulties they encountered in organising a meeting with representatives in comparison to a meeting with colleagues, including having to send paper

copies of documents prior to the meeting to all representatives, additional emails reminding representatives to attend and liaising with different university departments to ensure representatives received payment. While often finding these tasks frustrating, the professionals did not find them difficult; rather, it was the time required to complete the tasks that made them onerous:

“It is a lot of organisation. It’s not as simple as just kind of saying oh lets hold a group, you have to think of you know, setting the agenda, and sending all the information out in plenty of time, erm... then people say they haven’t got it because the hospital post systems are so rubbish and then you have to send it all out again, and erm... just you know coordinating things like that and finding the time when everyone is free, erm... can be quite time consuming really. Erm.. and then of course all the problems that come after of not getting their money and you are having to chase people all the time and things you know, for one meeting it takes up a good few hours of my time really.” (Rachel, RC)

In conjunction with the additional time it took to organise the meetings, professionals also identified ways in which having meaningful PPI in meetings could result in them lasting longer. They suggested that representatives might need more clarification and explanation than professionals, be more likely to raise issues that had not been thought of and be less concise in their explanations, all of which could lead to lengthier discussions and in turn longer meetings. These issues, combined with the potential need for representatives to have more frequent rest breaks and to arrange the meetings at a time and place convenient to them rather than for the professionals, increased the amount of a professional’s time given to any one meeting:

“It is a fact that if there are lay people in a meeting the meetings take longer.. because whether they ask for explanations or not and sometimes they will do, repeatedly, you do have to erm... take longer explaining things... and so meetings take longer which obviously means that... it puts people off attending or people have to leave half way through and ... so that is a very practical negative consequence it makes things more difficult to organise...[...]... it means the meetings sometimes have to be in the middle of the day if you are involving patients, or carers you, you can't easily start a meeting at 8.30, you know meetings with patients and carers traditionally are most successful, or certainly in my field, is they are in the middle of the day like you know 11.30 till 2.45 or something like that. It is a lot more time consuming. But these are all obvious in a sense practicalities and costs you know.” (Fred, NL)

Fred (NL) also suggested that some of the more tokenistic types of PPI were the result of professionals trying to minimise the time commitment to any given meeting:

“So a Professor on a committee may well do everything they possibly can to avoid getting anyone that is going to be argumentative, or make meetings take longer or erm.. put awkward points or view or put things on the agenda that you know are not what the Professor who is chairing the meeting is interested in. Not for, not because

they are evil, but because they are busy and they want to get business done and they have only got 2 hours for a meeting.”

As well as emphasising the additional time and complexity that PPI introduced to meetings, professionals also identified other practical components of ‘meaningful’ PPI that required their time. These included seeking training for themselves and the representatives, the process of recruiting representatives, support for representatives and allowing time for representatives to provide feedback:

“The problem is that it’s, you can’t expect people in the research development group to be able to get you feedback in 24 hours, 48 hours. Realistically they want a good couple of weeks, or a week to think about things properly, whereas a lot of the academics that we work with and researchers are much more used to, to working to deadlines, and so they probably don’t even start putting bits together until the week of a deadline and, and getting signatures and things all take time, so that has been quite difficult.” (Jess, NC¹⁵)

As alluded to by Fred (NL) above, it was a ‘fact’ accepted both by the professionals and representatives that professionals are very busy, with competing demands on their time: *“researchers are very busy people..[...]... my heart goes out to most researchers in a sense about, because, they are so busy and so to have another thing to do, to be able to just get this research out”* (Adel, NL). As such, they must prioritise how they spend their time. In addition, ‘doing’ PPI is not something that is traditionally allocated as part of a researcher’s academic role. It was evident that the professionals in my research sites believed that the benefits of PPI were worth the cost in time and as such were prepared to be engaged in the PPI process. This seems to mirror heavily Salmon et al’s (2007) research findings in relation to GPs (an accepted ‘busy’ group of professionals) and their decision making about the economy of their time. Salmon et al found that GPs attribute lack of time as their main reason for not engaging in research and that this was seen as morally acceptable. However, when the GPs could identify intrinsic clinical, personal or professional value in a research project, they would release some of their ‘own time’ or ‘work time’ in order to participate. In other words, professionals find time for activities that they personally value but do not find time for things that they do not value:

“I think they [professionals] have come round to that and thought actually, it’s not as bad as I thought you know, and so, it is erm, it seems to work..[...].. we have had to sort of like train them in a sense well look this is going to be beneficial for you, it isn’t just a tick box exercise, if you get the input and you are willing to take it on board, then surely your research is likely to succeed.” (Adel, NL)

¹⁵ NC= Network (and PPI) coordinator

The professionals in my sites clearly valued PPI enough to invest their time in the process. To determine the extent to which time acts as a barrier to PPI would require further investigation with professionals who choose not to partake in PPI, which was outside of the scope of this thesis.

As discussed in the Literature Review (see Section 1.6.1) added time commitment is often highlighted as a consequence of PPI, however there is very little detail about why PPI is time consuming (Boote, Baird, & Beecroft, 2010; Boote, Telford, & Cooper, 2002; Staniszewska, Jones, Newburn, & Marshall, 2007; Trivedi & Wykes, 2002). The professionals in my sites did not express concerns about PPI increasing the overall length of the research project (which to some extent might be compensated for by quicker recruitment) as suggested by Boote, Telford and Cooper (2002), but rather about the amount of their own time needed. Being aware of exactly how PPI incurs additional time allows for it to be budgeted and planned for.

4.5.4 Blurring of roles

In Chapter 3 when describing the PPI process in the comparator network, I raised the point that Jess and Tom did not feel they treated the representatives in the same way they would other colleagues (see Section 3.2). They linked this to the issue of professional boundaries and the blurring of their roles as researchers and clinicians. While issues of role uncertainty and clarity were touched on by many different professionals, as reflected in the latter parts of this section, they were particularly important for Jess (SS1), Tom (SS1) and Nick (CS1) who were my only informants with a clinical relationship with the representatives outside of the research. The approach to PPI adopted by the comparator networks involved frequent sustained interactions with the same representatives. Tom and Jess felt this compounded difficulties related to professional boundaries, raising the dilemma of how to maintain a working and potentially a more personal relationship, with representatives while still maintaining enough professional distance to work with them in a clinician-patient capacity. Jess and Tom both gave long detailed descriptions of their concerns:

“The other thing that I found really hard is that, as a clinician or as a doctor, you’re trained to maintain professional boundaries. That these are your patients that you care for them, you provide a service to them, and so I found it increasingly different, difficult that these people I was beginning to care about, I cared about them a lot, um, and I worried that we saw them in a research capacity, but then Tom would see them in clinic or I would see them in my other role, un, and I find that, I found that really difficult but actually I am beginning to become more comfortable with that. ..[.]. I actually have begun to like the fact that they are my friends and not just

people of the RDG but I to start with I found that very, very difficult...[.]. I do think that that is a really important point about involving people in research that, that you will, they will become your friends, you will begin to care, and you can't then provide them a service. So, yeh I guess I found that really hard. Lots of people have since told me that I guess its expected to kind of run into these kind of troubles, if you are going to get close to a group of patients, and you can't expect to please everybody all of the time. So I guess they for me are the two flip sides, that I don't feel like we are giving them enough, and I think sometimes there are issues about professional boundaries, and that you have to acknowledge whether you are just going to forget them, or whether you are going to try and maintain them for the benefit of what you are doing. But I think people need to have that discussion with themselves." (Jess, NC)

"Then people ask about er professional barriers, so people ask about epilepsy advice, you may have met them once in clinic, you may not know them at all, you may know a bit about their epilepsy from what we have talked at the table you may not know and you have got to be very careful about what is general sensible advice about epilepsy and what is specific advice. And particularly you don't want to be getting sucked into giving advice about changing drugs, urm drug doses particularly if you are not the regular er physician, it's much safer to say this is sensible advice, contact somebody or you know, or I will arrange to see you, I will arrange a clinic appointment, probably I won't arrange to see you because I think once I see them outside uerm I would probably prefer a um colleague to see them in clinic. Um I wouldn't have a big problem with it but I think it might just be a little bit easier. Um I mean in terms of professional boundaries, yep, we are not dating anybody on the group you know, its, its, we're not that intimate but you could end up giving somebody a lift to the train station and you get a little bit of your professional identity chipped away when they are sitting next to you in the car and they are seeing you, you know are sitting down having a cup of coffee and maybe that's a good thing, but I have to be aware that it is happening. Erm, so we don't give out our mobile phone numbers to people, in the group. Urm, and yet I would accept a number from someone else, or their e-mail address and so there is always a bit of power imbalance there, you wouldn't say it was a partnership and they are all co-equals, but there is a bit of a power imbalance because I don't want to lose the ability to be their physician, ur their clinician at any stage." (Tom, CP)

That the RDG group was meant to be led by the representatives and only facilitated by Tom and Jess also exacerbated role issues. They were not meant to be present in an authoritative or leading role. However, they felt they needed to take control of and guide the group to ensure it achieved its aims and acted on their suggestions, and these were two contradictory positions to hold. This difficulty did not seem to arise in the other sites. Rather the professionals at the other sites seemed to pre-empt potential role uncertainty and boundary complexities by having clear views on what was their role and what was the representatives. Therefore, many of the professionals did not think that the representatives needed extensive research knowledge as they considered it the professional's role to direct the research process and the representative's role to provide experientially based advice.

The other professionals also avoided issues of power discrepancy as they did not aim to be equal in the decision making process.

The influence of the particular PPI approach adopted on boundary complexities is demonstrated by Nick's account (the other professional with a clinician-patient relationship with his representatives). Nick did not express the same concerns about boundary issues as Tom and Jess. However, he believed that his role as the representatives' doctor had an inhibiting effect on the PPI process, that because they were used to being his patients they were less likely to be forthcoming in their discussions (this is something I noted in my fieldnotes and was also raised by the representatives, see Section 5.6). Nick found this frustrating because of the time it took in meetings to get representatives to relax enough to contribute, and also that he was present at the meetings in the first place because he wanted to hear their opinions:

"I often don't go for the whole meeting, in part because I think I might inhibit what they would say and they might be more open when just Rachel is there. Because I think there is still this doctor patient thing going on, I don't know will it ever go but erm... I think at the moment the reality is lagging behind our aspirations. Erm... it maybe my fault you know that I am somehow not, fault is a bit [30.26] sounds a bit depressing anyway maybe that I am not involving them sub optimally or... or, somehow I am not communicating clearly enough what does it matter but it still feels, like every time we meet I have to reannounce the framework you know, explicitly state, this research... we are meeting here because we are really interested in what you have got to say and so you know I have to kind of you know officially, erm... empower them to speak you know and if, if the situation was what it is intended to be, then that shouldn't be necessary but it feels like it is. Maybe if I just sat there and said nothing they would start piping up but I still feel the need to announce the sort of you know to define the setting, in this setting it is ok for you to speak, I am a doctor but you know I really am dependent on you and you know you really must have your views and very much cherish your input all this sort of stuff... what Rachel tells me and you know it always seems that the more interesting stuff happens after I have left so you know that's fine. Initially I think I was there for the full first meeting probably but after that I started to only come in for the beginning or part of it. ... sociology seems to get in the way, of what we want to achieve you know, we want to achieve this level playing field partnership situation, but it just isn't there, ((laughs)) it ain't possible, sociologically, so you have to kind of bridge this gap and it involves a lot of heavy lifting on both sides and so the patients have to give themselves a push I am going to say this although it's the doctor here you know although he knows so much more than me but I am just going to risk it." (Nick)

This frustration about representatives not voicing their opinion was echoed by some of the other professionals. In Chapter 5 I address this issue from the representatives' perspective and discuss some of the reasons representatives believed that professionals would prefer to hear from their colleagues rather than from them, and as such might refrain from

speaking. When I discussed this with the professionals, they adamantly disagreed, saying that in this context they would prefer to hear from the representatives as they have more opportunities to access the views of their fellow professionals than they do to access the views of representatives:

“Yes but we get professionals’ views all the time, we need the patients view ((laughs)) there needs to be time set aside, or there needs to be equity of access to comment really.” (Alex, ND)

4.5.5 Disruption to academic norms.

Another difficulty that professionals spoke of was that while, logically, they understood that representatives might not know the cultural codes of behaviour within the research context, they were still uncomfortable or offended when these ‘unwritten’ rules were violated by representatives. Most of the rules that professionals were sensitive about surrounded conduct in meetings. They placed importance on being punctual when attending a meeting, sending apologies in advance of non-attendance or anticipated lateness, being prepared by reading relevant documents, talking for a short length of time, completing tasks post-meeting that you agreed to by a certain date (and rearranging the date if you cannot make it):

“Sometimes you kind of get a group and it’s just the same people saying things really and a lot of them just sit back and as much as you encourage them, they are not necessarily very forthcoming and then some people don’t turn up on the day and things like that and you think well, if you are being paid then that is a sort of professional role and maybe, they could, I mean I, then I have sent them off with things and say you know, and can you send me your feedback and these things and they haven’t done, so they kind of attend the meetings and they come along, but I am not necessarily sure that they all put in the amount of effort that I would do if somebody was giving me £50 to do something.” (Rachel, RC)

Not adhering to these rules of conduct was considered rude by the professionals and cast representatives (and, equally other professionals) in a ‘*poor light*’. Charlie (NL) noted that conforming to these rules might be difficult for the representatives as a result of their condition or responsibilities as a patient or carer:

“It just comes down to culture, people having mental health problems, people forgetting what time you know, what time the meeting is, where it was, what is it about.” (Charlie, NL)

Another key academic norm was the importance of evidence-based practice. The moral justification for undertaking PPI suggests that PPI should happen whether or not it has an impact on the research process, with the more vocal PPI proponents arguing that it goes

against the ethos of PPI to try and measure impact at all¹⁶. This perspective does not fit easily within a biomedical culture based on evidence and accountability:

“You have got to be accountable, if you said you are doing something then, you have got to do it...[...]... I mean rightly so the Department of Health are saying what actually is PPI doing? I am giving you a million pounds a year, for the networks what is it that it is achieving, you know and we have to move away from this, you know erm, oh well we helped, we helped design a leaflet to promote the network, well that is not worth that amount.” (Adele, NL)

4.5.6 Worrying about getting it right

In addition to having concerns about “*those*” representatives, professional identity and demands on their time, professionals were uncertain about different areas of the PPI process and their role within it. Many of the professionals admitted that this uncertainty made them worry and question their decisions and behaviours with regard to PPI, emphasising the potential for negative emotional effects of PPI on the researchers. Some of these worries were specific to the individual or context and only expressed by one or two of the professionals. For example, Rachel (RC), who was a researcher and also a clinician, spoke of worrying when one of her representatives did not know they were still having seizures and was unsure whether to broach the subject, as the representative was not interacting with her as a patient and it was not her role to advise them in this context. As discussed below other worries such as the ‘representativeness’ of the representatives and upsetting representatives were much more prevalent.

As evidenced in Chapter 3, some of the professionals had clear ideas about who should and should not be a representative, while others were less certain. The source of this anxiety seemed to be a concern about how *representative* a representative can be expected to be. Representativeness holds a specific meaning in the context of quantitative research, with studies being designed to obtain a sample that truly reflects the wider population. In the context of the epilepsy research community, people with epilepsy were seen by professionals as having extremely varied experiences and views based on age, gender, type of epilepsy, education, profession, treatment and social class. Professionals therefore worried that the people they were selecting to involve were not really representative of the epilepsy community as a whole:

“I think the epilepsy experience, is varied. We have got um carers of people with epilepsy there, erm both partners and people who work in the care system, um

¹⁶ This was evident from my fieldnotes at the INVOLVE conference 2010, not within my sites.

somebody who has lost a brother to an epilepsy death, parents who have lost their son to an epilepsy death, a person with mild learning difficulties and his mother, umm a chap who with learning difficulties who comes on his own, we have eerm, people with really mild epilepsy, a couple of seizures and nothing more. People who have had epilepsy improved with surgery and no more seizures, and people with really difficult epilepsy that keeps coming and coming. And I don't think any one of them could give you the patient experience." (Tom, CP)

This, in turn, led to professionals worrying that they were being tokenistic or not engaging in meaningful PPI. The way most of the professionals dealt with this worry was either to have as many representatives as possible (SS1 and CS1¹⁷) or to accept that achieving 'real' representativeness was impossible and to select representatives that they felt could have the most effective input in a given situation (UKERN and CS2):

"PPI suffers from language being used in a very bad way. Like a user representative for example, no user can be a representative you know, erm... people who use services any service, are always diverse as anyone else. And no one is really a representative, they're a patient." (Charlie, NL)

"It is inevitable that there are going to be a range of views and a range of constituency across epilepsy, er, I think we have to, we have to accept that and we have to do the best that we can to ensure umm a wide selection of view are taken, but at the end of the day we can only accommodate a certain number of people in the study groups be that be patient public or clinicians and researchers, it means to take a similar view that you know there are a number of clinical domains er which aren't necessarily represented in the network as it stands. So it is not really specific to PPI its er it is, it is a the brood scope and heterogeneity of epilepsy, within research and society." (Alex ND & CP)

The professionals concerns about how 'representative' a representatives can and should be are reflected within the PPI literature (Entwistle, Sowden, & Watt, 1998; Entwistle et al., 1998; Rhodes et al., 2002).

In comparison to professionals' worries about representativeness, their worry about not wanting to 'upset' the representatives is harder to describe. It was clear that professionals worried about their interactions with representatives far more than they did with their colleagues. In some cases this worry seemed to directly impact on the professionals' behaviour and it seemed to be consistently present for some of the professionals, but it was not always clear why. Alex (ND & CP) suggested that it is because he felt a level of responsibility for the representatives, and in his clinical role as a neurologist he was used to taking care of patients:

¹⁷ CS1= child site one, CS2= Child site two, SS1= sibling site one.

Alex “You do feel like you have got a strange responsibility actually.. erm... it's quite different erm..., erm... and I can't necessarily articulate why but it's quite different having a responsibility for one's fellow academics as opposed to erm... the patient and public representatives there is a kind of different feeling of responsibility I think.

Beth *I know you just said it's hard to say why but...*

Alex Don't know, don't know perhaps I want to, perhaps I am being too paternalistic. Erm... and I guess in part they are patients in a sense they might be, in my subconscious they might be half way between patient and professional colleague. That's probably my problem that I need to deal with ((laughs)) but erm... there you are I have articulated that.”

This responsibility Alex felt seemed to hold true across the different groups of professionals. It seems that the very act of choosing the representatives and bringing them into the project made the professionals feel responsible for their welfare in a way that did not hold true for fellow professionals. This may have been due to professionals' awareness of the power discrepancies within the group; however I did not identify and address this during data collection.

Les (ND) suggested another reason for worrying about representatives was the acknowledgment that they might have a personal and emotional investment in the research that the professionals did not have. They were therefore seen as more vulnerable to being upset on a personal level, by the rejection of their ideas or by the language the professionals used:

“I think that their position is quite vulnerable, vulnerable because of that. Urm, and, because people are only there to represent themselves, they have got sometimes a personal reason to be there, so I have mentioned the mother and father who are there because their son died of an, of a epilepsy related death, a SUDEP¹⁸ death and they would be particularly vulnerable to any project involving SUDEP and then there is also somebody who has lost their brother there, and so you know if we put in money for one of those kind of projects, and it, it, was deemed to be not scientifically strong enough, or erm if they thought they were supporting something that was going to give a more positive answer or more definite answer and it never got there I think people can be quite vulnerable.” (Tom, CP)

“Sometimes they can get things wrong and go home insulted, or go home, er, just thinking they have, you know they feel as though you haven't understood something and their backs go up and the barriers go up and so, there are... Well I think it just comes down to sometimes as professionals you use language which is scientific eerm and so, for example if we say mutations in the gene, we know what that means but to the lay public that can mean several different things. Urrr and, um, and, I think you know sometimes patients can get it wrong from that perspective. Urm I think there has been one situation ahh, where you know Jess has rightly said to

¹⁸ SUDEP stands for Sudden Unexplained Death in Epilepsy

patients look we can't form, buddy, buddy relationships here, we do have to make sure that we guide you rather than form you know, long life friendships and I think one or two got were insulted by that. So I think you know, so sometimes we get it wrong, in terms of language, um in terms of over scientific presentation, misinterpretations." (Les, ND)

As touched upon when discussing the professionals' concerns about 'those representatives', professionals were aware that some of the representatives were ill, and as such they did not want to draw attention to or exacerbate the symptoms of their illness and in doing so risk causing offence or distress. Other ways in which the professionals worried that the process of PPI could cause distress to the representatives included having them involved in a bid that then did not get funding, not being able to act upon their suggestions, representatives becoming frustrated over the slow pace of the research (or network), being insulted, failing to communicate in a way they understand and introducing new information on their condition which could lead to increased anxiety on the part of the representatives.

4.5.7 Feeling demonised

It is not only representatives who might feel 'insulted' during their interactions with the professionals. A small number of the professionals reported experiencing interactions with representatives that left them feeling 'demonised' and 'upset':

'This woman came up to me and said I was only interested in my career, that I was not doing research to help people with epilepsy, that I was only interested in getting paid, that I did not care about them.' (Ann, supervisor, paraphrased in fieldnotes)

"I had an e-mail from the woman which was aggressive um, and nasty and horrible and told me that um, said I had the wrong attitude, that she didn't respect me anymore, that I should be ashamed of myself that I wanted to work in the health profession if I had um, issues with boundaries, and that upset me so much." (Jess, NC)

'She [a representative] came up to me and was like 'What do you know, you have not been though it' and I thought well actually I have been though years of training and worked in this field for a long time. It felt like she was telling me that was worth nothing' (researcher, paraphrased in fieldnotes from INVOLVE conference)

While this was the least prevalent challenge in my data it seems to have been particularly upsetting for those involved. It appears that the professionals felt the representatives in question were directly and fundamentally challenging or disrespecting their professional and in some cases their personal identity.

4.6 Discussion

In this chapter I have described the professionals' experiences and perceptions of PPI, demonstrating that they viewed increasing the relevance of research as the primary purpose and overarching motivation for PPI, rather than any moral or political justifications. Overall the professionals had a largely positive attitude towards PPI. However, they were 'sceptical' about its impacts and unsure about the best methods of implementation. Ways in which the professionals believed that PPI could benefit the research process included: helping to gain funding and ethical approval, increased relevance, and increased participant recruitment and retention, all of which are congruent with those given in the PPI literature (see Section 1.6.1). The professionals rarely identified any benefits to themselves outside of the research process. They did however identify a range of personal as well as academic challenges linked to PPI, including: working with 'those' representatives, issues of tokenism, time commitments, blurring of academic roles, disruption to academic norms, worry about getting it right and feeling demonised,

The professionals differentiated between 'tokenistic' and 'meaningful' involvement, advocating the use of strategic meaningful PPI in some stages of the research process over potentially tokenistic PPI in all stages 'for the sake of it'. This approach to PPI conflicts with the Department of Health's policy (2006) to have PPI in *all stages* of the research process. It also does not fit easily within the models of involvement that conceptualise power over outcome as equivalent to level of involvement (see Section 1.4.1) because how 'meaningful' the involvement is perceived to be by professionals appears to have little to do with the degree of power over outcome.

Issues raised in this chapter are explored in more depth in the discussion chapter. The discussion chapter also takes into account the representatives experiences as described in the following chapter.

Chapter 5. Representatives' experiences and perceptions of PPI

5.1 Introduction

In Chapter 3 I focused on the professionals' site-specific motivations and decision making processes around PPI. This was then built upon in Chapter 4 where I explored more broadly the professionals' experiences of PPI. The current chapter shifts the focus from the professionals to the patient and public representatives, describing and interpreting their experiences of, and reflections on, PPI.

Mirroring the presentation of the professionals' data in Chapter 4, in this chapter I draw upon all of the data from the representatives. As my interactions with the CCRN PPI network leads (SS2) and the clinical trial (CS2) did not result in any direct interactions with PPI representatives, this chapter addresses the representatives in the remaining three sites: UKERN, the comparator epilepsy network (SS1) and the intervention study (CS1). As described in Chapter 2, this consists of 23 interviews with 17 representatives and fieldnotes from site observations. I will first explore how representatives described their understanding and conceptualisation of PPI. I go on to discuss their motivations for involvement and the personal benefits they identified. Issues surrounding 'confidence' are then discussed in depth, as this seemed to be a key influence in how the representatives experienced PPI. Lastly, I discuss the challenges that the representatives experienced.

Throughout this chapter any differences in reported experiences across sites are highlighted to further address research objective 4: *'To compare different approaches of implementing PPI'* from the representatives' point of view, building on the information in Chapter 4. This chapter also draws attention to how the representatives' experiences: *'compare and contrast to the theoretical underpinnings of PPI'* (research Objective 2).

5.2 Understanding of PPI

In contrast to the professionals, the representatives did not appear to differentiate clearly between 'What is PPI?', 'What is the purpose of PPI?' and 'What are the benefits of PPI to the researchers and the research process?' Their responses to these questions were

enmeshed. Therefore I present the findings in this chapter in a way that reflects how the representatives expressed their understanding of PPI.

5.2.1 What is the purpose of PPI?

Many of the representatives admitted to being unsure about the purpose of PPI prior to their own involvement in research. Those who described having some awareness said that they developed their understanding by observing PPI in panels and groups on which they had fulfilled a professional role (these were mainly the UKERN representatives). Others described developing their understanding of PPI through experiencing it themselves as a representative. Consequently, some representatives were less confident in articulating their understanding of PPI than the professionals were:

Beth: “What is your understanding of what public patient involvement in research is?”

Faye: Really limited, really limited I suppose. Erm, well maybe it’s not I don’t know, maybe I am waffling, erm I suppose because of the service user involvement in mental health and learning disabilities that I know a little bit about it I suppose my, my understanding is probably not as limited as I am portraying it.” (UKERN)

When discussing the purpose of PPI the representatives tended to situate it outside of the research context and spoke of PPI within the NHS, service improvement and other government schemes:

“Public patient involvement. Involvement in various ways in, I suppose, the National Health Service. I guess it might be in other areas of government I don’t know, I know that they have been advertising for the local hospital at one stage, erm, and in this instance, they are wanting us included in the planning of the research programmes.” (Hazel, UKERN)

“I was sort of vaguely aware that in the wider world that you know there is much more listening to erm, the public, I sort of have been to a couple of meetings for a local mental health trust, they are trying to set up themselves as a foundation trust, and you know again beginning to realise that they want carers and patients involvement in that... The NHS was across the board if you like wanting patient input, patient and public input.” (Katie, UKERN)

Like the professionals, the majority of representatives agreed on what they perceived to be the purpose of PPI. Instead of focusing on increasing the relevance of the research as the professionals did, they tended to take the position that the primary function of PPI was for professionals to get a ‘*different point of view*’ or more specifically a ‘*patient’s perspective*’. Accessing a different point of view was seen by the representatives as resulting from their own experiential knowledge of epilepsy but also, in some cases, from the perspective of a

non-professionally trained person. Both of these factors were seen to allow representatives to identify issues that would not be in the professionals' purview:

Beth: "So from the doctor's point of view or from the researcher's point of view what do you think the point of them asking patients' perspectives is?"

Claire They are only seeing it from the doctor's point of view, they see the patients all the time, but they don't know how patients may feel about the information they are being given, the treatment they are being asked to undertake, you know, certain, a lot of aspects of what they might have to go through and it's not always possible for a doctor to see the research in that way because they have obviously been through training for however many years it is, so they can see it from their point of view but not necessarily, take that step back and see it from the patient's perspective." (CS1)

Beth "So an advantage of having patient involvement is that they might point things out that a clinical person might not realise?"

Ron Or thought about, or have thought about. I mean it's like any committee of people, if you get a body of opinion, generally speaking there might be 3 or 4 people who think the same thing but there will be always 1 or 2 or 1, who will think of something different, and I think to have a range of opinions, be it scientific, psychological, erm, just general public involvement will give a different view of that, whatever it might be. I think the whole, the conclusions that you would draw as a group from all that information is going to be more, erm, what's the word, more precise, and more likely to be realistic." (UKERN)

One of the advantages that the representatives believed that their perspective could bring to the research process was a 'de-jargoning' of the language used. The general consensus was that professionals have a tendency to talk in a way that 'normal' people do not understand and it was their role as a representative to help professionals communicate in a way that would make sense to a wider audience:

"The people the field of neurology that I have come across are extremely clever, and are extremely.. I want to use the word gifted at what they do, however, they don't have very good people skills so when they are explaining something to a patient, it is matter of fact, it's all kind of cut and dry and they will use a lot of Latin in there, and people will go ok, ok, and then they will leave and they will be like, oh what? ((laughs)) so, erm, we want to make sure, my personal feeling is part of this group is to try and cut that out as much as possible, yet still get as much reliable information in there as possible." (Jim, CS1)

"If you have got somebody in that room who is going to be brave enough because you are going to need somebody with a bit of balls ((laughs)) really to say I am really sorry but I haven't got a bloody clue what you are talking about ..[.]. Not to be irksome but because that is our role, that's what we are, that is part of our role." (Faye, UKERN)

Between them the representatives identified two distinct ways that simplified, de-jargoned language could positively impact on the research process. Firstly they felt that it could improve study recruitment, because if potential participants understood what was being presented to them they would be more inclined to agree to take part. Also, they would be less likely to be offended or discouraged from participation by the language used in the research documentation. Representatives also spoke of how they might be able to provide suggestions on how to improve recruitment outside the issue of the language used, for example by giving suggestions on the way potential participants were approached:

“They kept using the word erm, psychogenic and you know ‘psycho’ the word ‘psycho’ a lot in things, erm, and I personally feel that if you tell someone they are a psycho in the opening line of a statement, they are going to not be interested in what you have got to say. Because this is a mental condition, people already have you know, preconceived ideas of what a mental condition is, and I think if you go at somebody who has just been freshly diagnosed with a mental condition and use the word psycho you are going to freak them out and they are not going to be interested in ((laughs)) anything that you have got to say from there on in because all they will hear is that word. So I suggested they change that and they have changed that, and I think that will now have a more positive impact on the people that they are trying to target because they won’t be so frightened just by reading the first opening sentence.” (Moira, CS1)

“Well there definitely things that you can comment on... you know the approach given to erm... to inviting people with epilepsy to take part in the research for instance, definitely have thoughts on how that might be best approached.” (Katie, UKERN)

Secondly, it was suggested that by altering the language, the findings of the research could be disseminated to a wider audience, thus increasing its chance of having an impact and helping to ensure that researchers were accountable to the wider public:

Beth: “So, if you are then going to be recruiting someone into a study, you need to be able to explain to them in clear ways what they are getting involved in, so using this excuse of well it's difficult to explain...”

Faye ...Absolutely but not only that, if you want the world to know, how are you going to tell the world. You can't just publish it in one of your obscure scientific journals and hope that some journalist will pick it up and interpret it for you, there is a whole world who needs to know what you are doing really. They just say, oh it's very complicated that is just not good enough and it also leaves you open to not being accountable to people and I think this is the same here.” (UKERN)

The majority of tasks that representatives had undertaken within their PPI roles required them to give feedback on the readability of protocols and participant information. It therefore made sense that they presented this as one of the main benefits of PPI. Similarly, representatives who had made suggestions on the research design process, for example

those in CS1, or on relevance or priority setting like those in the UKERN, were much more likely to have mentioned these as benefits of PPI.

In conjunction with the representatives' belief that their experiential knowledge of epilepsy would help the research process, there was a general perception that PPI would also more broadly benefit the professionals. This was because it provided them with an opportunity to interact with representatives outside of the normal clinical context, increasing their knowledge of their patients' experiences and, in turn, improving the service they provided. This issue was amplified by the observation that most doctor-patient interactions are time-constrained, and all of the representatives had experienced interactions with busy or dismissive health professionals:

"I think it [PPI] really does help because you learn things at university and you learn things at medical school and you see people in a 10 minute consultation, and you can't gain information, you don't get what it feels like to have it, and I do think it's really important that people who are offering a service, or interacting with people who have a condition, have a certain amount of empathy to what it feels like to live with it ..[.]. If you have got knowledge, more of knowledge from this side it helps you deliver a better service. And I think that, people participating in research who have the condition that is being researched, it does help people to get more of an understanding of what it is like on a day to day basis, then they can deliver a better service." (Moir, CS1)

"I think for Tom [CP,SS1], he, he listens and he hears people, coming from the heart if you know, what I am saying like and urm the more people he hears, and the different things he hears about, that is bound to have an effect on him, and hopefully that will be fed back to his other peers, or whatever it is like you know other doctors, and so that can only improve the service that is being given." (Matt, SS1)

5.2.2 What is meaningful PPI?

When conceptualising and reflecting on PPI the representatives, like the professionals, drew a distinction between what is meaningful PPI and what is tokenistic PPI. The representatives in my sites remarked that meaningful involvement only occurred when they *could* potentially have an impact on what they were involved in; to an extent whether or not they actually *did* have an impact was secondary. This was particularly pertinent as resulting from the moral and ethical justifications for PPI, there were a number of professionals who strongly believed PPI should occur regardless of whether not it made an impact on the research process or those involved (see Section 1.4.2)¹⁹. In contrast the representatives viewed this form of involvement as tokenistic and a waste of time:

¹⁹ This was particularly apparent in my fieldnotes from the 2010 INVOLVE conference rather than within my site specific data.

“We have made suggestions and they haven’t changed them and it’s disappointing, but they say, they say things like oh this is the set structure and we can’t alter it, you just think, well ok, you have to kind of accept it, but sometimes I think why did you ask us if you can’t change it. Why would you ask somebody their opinion of something if it can’t be altered, because it can’t be altered so it doesn’t really matter what somebody else’s opinion of it is. So, because if you are going to give somebody a criticism about something you need to know that it is going to be changed, and some things that we have suggested of like wording or, you know this question should be added, when they have done questionnaires we have said this question should be added, and they said well we can’t because it’s a set number of questions and those kind of things. It seems like a pointless thing to do really ((laughs)) what’s the point?” (Moir, CS1)

As explained in Chapter 4, the professionals believed that meaningful involvement occurred when representatives had valid opportunities to express their views. The representatives built on this idea, giving examples of situations that were and were not ‘valid’ from their perspective. Understanding what they were being asked to comment on was seen as particularly important. This did not necessarily mean understanding all of the detail of the research or medical components. Rather it meant having enough information to place the research in context and enough direction to know where to direct their focus or attention:

“If you just give somebody a piece of paper and say read this and then tell me what you think, they don't know what they are telling you, what they think about in context because they could just say well it's a very nice paper actually, I quite like that, or it makes no sense to me, it has nothing that I can tie onto..[..]. But if I gave that paperwork to my parents, and said what do you think... you would at least need to narrow their field of judgement, so that they were making a decision on something that was pertinent and relevant to what you wanted and whether you do that through giving them a bit of a research background or whether you do that through just giving them a bit of a, clinical background I don't know or whether you just say to them, do you think it's important for you to know this.. I don't know.” (Faye, UKERN)

“I still might not know or understand is the direction and I think it’s just a lack of knowledge, I am sure that if somebody had, if I sat down and explained to me right this is what we are trying to do, I would have got that.” (Paul, SS1)

The UKERN representatives felt that they had some sense of the context of the research as a result of their professional backgrounds but that their understanding was further developed by the training day and their attendance at the International League Against Epilepsy (ILAE) conference. The representatives from the Comparator Epilepsy Network found that listening to the researchers discuss their area in general before being asked to make comments on a particular project provided a frame of reference that they would not otherwise have had.

Having the opportunity to give their opinion and it being listened to was also seen as imperative to meaningful involvement. This might seem self-evident, but just because a representative was present at a meeting or part of a group did not mean that they had the opportunity or the ability to contribute:

“Some groups erm I have been involved with are actually larger and you can feel that you are not actually getting your own, you know getting your point across because there is like if there is 20 people in the group, then you have got a lot of people talking and you have only got a short amount of time to actually erm, talk about what you erm, you know want to talk about. It can be quite difficult because, if like, in one group I go to one person is erm, quite chatty.” (Claire, CS1)

Hazel for example was told that she was going to be asked to comment on some documents; however due to time constraints the group leader did the work herself rather than sending it out to the group. While she understood the logic she felt it defeated the point of having her and her fellow representative as part of the group:

“I know that when you have got somebody in who really doesn't have the same knowledge and understanding as you, it's much quicker to do it yourself, or just for one person or two people to do it isn't it? Erm.. but I guess that's not what it's supposed to be about is it? It is disappointing because I think we both wanted to be involved but erm... it's not really happened...[..].It makes it [PPI], it actually has made me feel that it's just a paper exercise frankly and I don't say that the people or certainly not all the people who are involved erm... are just going through the motions but it feels that perhaps, it is something that has come down from government that you are supposed to do and it ticks boxes and we are being ticked off, but we are not actually being involved.” (Hazel, UKERN)

In turn, once the representatives had the opportunity to give their opinion they wanted to be listened to and have their opinions taken into consideration by the professionals. The majority of the representatives felt that the professionals involved in the different sites actively listened to what they had to say. This perception was reinforced when the professionals took time to explain why they were not intending to incorporate some of their suggestions:

“My recollection is that there was no difficulty, in you know, having a discussion that involved everybody and that everybody contributed and everybody listened I didn't think that was a problem at all.” (David, UKERN)

“Actually feeling like people listen to you, because you know when Rachel (RC) is there she is taking notes so erm, you know that she is actually listening to what you are saying and, taking on board the comments that you are actually making. So that's good, so it feels like you know you are, your involvement and the time that you are spending actually erm, getting involved with this is not being wasted..[..]... you know if Nick doesn't really agree with you, he will give you an indication of why he doesn't agree with that or why he doesn't think that is a good way of doing things, which from my point of view, I prefer because even if you know he is not going to take on board what you are saying, he is telling you why he is not you know, why all the

reasons behind it, which is better than just being told no we don't want to do it like that, end of conversation." (Claire, CS1)

Representatives also focused on the meaningfulness of the small changes that they could make. They did not perceive the purpose of PPI as being to make wholesale changes, rather that by 'tweaking' words and making adjustments to process they could have substantial impact:

"Hopefully when the research is completed, you can have a hand in actually erm, shaping the way things are done. You know probably not in a major way, but in a, a small way that may help out the patients in ways that may not have been thought about." (Claire, CS1)

5.3 Motivations and benefits

I found it surprising that representatives' motivations for taking up a PPI role did not appear to be touched upon in the existing literature. In my own study, the representatives' motivations for involvement influenced their experience and in light of the concerns some of the professionals expressed about the motivations for involvement of 'those representatives', insight into the representatives' motivations seems particularly pertinent.

Representatives seemed to have a sense that they should say they were motivated by the wish to 'give back' to the research and medical community which had treated them: "*perhaps giving a bit back is what you should say isn't it?*" (Ron, UKERN) or, that they should only be altruistically motivated to 'help' others: "*The hope that it benefits other people, and benefits me in the future. So it's perhaps not as altruistic as it originally sounds*" (Katie, UKERN). While giving back and helping others were partial motivators for some, they were not the only reasons for their involvement. The representatives identified four main motivations for their involvement: personal interest, making a difference, restitution and value. Representatives also identified the opportunity to learn and opportunities for social interaction as additional benefits of PPI. I will now discuss each of these in more detail.

5.3.1 Personal interest

The most commonly stated reason for involvement by representatives was that they were 'interested' in the area. When I asked them 'how/why did you get involved in [site name]?', nearly all of the representatives responded with a variation of: "*she asked me if that was something I was interested in, you know getting involved with, and I said, yes I was*" (Claire, CS1). They attributed their interest in both the topic of epilepsy and the research aspects to their own experiences and academic curiosity:

"I had been reading research articles because I just wanted to find out more about epilepsy generally. I suppose I am sort of interested in sort of [laughs] academic stuff a bit anyway, so it was sort of a joint thing of erm you know, wanting to find out more about epilepsy and, erm, you know interested in the fact that people you know people's research and also you know slightly personal academic reasons as well I guess." (Katie, UKERN)

"The whole thing of epilepsy per se is an interest because of my family connections and also my community work ...[...]. it's an interest in addition to the interest I have already got in that it will get my head back into academia to a degree, I like reading scientific ...[...]. I am doing it for self-interest. I have to be honest; I am interested, genuinely interested in it, it's my favourite subject." (Ron, UKERN)

"It's also, you get to be interested in it [in the condition], don't you? So we thought this is a way of, we had the time, and we were interested so. We could maybe contribute something." (Jill, SS1)

In turn, the representatives identified 'finding it interesting' as one of the main benefits of their involvement:

"Benefits? I find it fascinating hearing what the research proposals that are going on. I like being able to express my views, erm, I like looking at research proposals, I have always been interested, sort of interested not involved, but I guess my academic background I think by nature too, I am, I like to analyse things." (Hazel, UKERN)

"It's been quite interesting, um, you know, Jess (NC) and Tom (CP) um, have had important doctors and specialists there doing saying their, their pet subject then if you like and what the ideas that they want to see, put on, or put in or however you want to word it, um, so it's been quite interesting for us." (Chris, SS1)

5.3.2 Making a difference

Another of the representatives' recurring motivations for involvement was to 'make a difference'. However, each representative's motivation for wishing to do so varied. Faye's (UKERN) wish to make a difference came from a wider belief that if you are unhappy with something you should at least try to change it:

"It's a part of a personal political stance for me, I am a great believer in if you don't like something, or if you are not happy with something then you should try and change it. I don't believe you can complain about something if you sit on your arse and don't do anything about it. So, it just gives me a sense that I have a right to moan [laughs]. No but it's more, I think it's more about I have a sense that I am trying to make a difference somewhere along the line, and that feels better for me it just feels like I am trying somehow."

For Sam (SS1), who had recently lost his job, after his epilepsy changed from being well controlled to uncontrolled and having also been diagnosed with depression, he felt that his self-worth rested on his ability to affect the world around him:

"I can still have an effect, I can have an effect on how people can possibly benefit...[...].speaking as a person who would love to get involved, in research, because it will make a difference, that's really why I wanted to get involved with

research is that I could make a difference for, well I say my fellow man, but people who are, people like myself who are suffering with epilepsy, ..[...].... being involved in something it makes a tremendous difference to your personality, to your sense of belonging...[...].. I felt a lot more positive, when I was involved. That's on a personal basis, really, I felt a lot more erm, (s4) enthusiastic, I had the opportunity to help others."

For Rose (UKERN) the chance to make a difference helped her feel less powerless in a situation where she could not directly help someone she loved:

"Having the kind of knowledge of my brother's... the issues for my brother, and what it's like for someone whose epilepsy isn't controlled and erm... has you know sort of complex epilepsy erm... I felt that I could perhaps represent him to some degree and it might be helpful erm... it's something I can do. Because sometimes you know it feels very difficult to know what you can do to help and it's quite hard, you know you feel a bit powerless really when you are watching somebody have a difficult time...[...].. It's just being able to do something practical.. Yes it doesn't probably make a difference to his life (laughs) but, it makes me feel like I am doing something I suppose."

The other reason articulated for wanting to make a difference was to help others, and potentially themselves, by improved research and, in turn, services and treatments:

"To see if my 10 penneth I could put in, would anyone could relate to it and either help me or help them you know." (Matt, SS1)

"It is just exciting to think that you, you can really, or you should be able to, really, really help people." (Sam, SS1)

As Moira (CS1) explained, one of the main reasons for wanting to help others was because she knew what it felt like when things did not go as you would like and she wanted to help prevent others having the same experience she did. This seemed to be true for several of the representatives:

"You can potentially help a lot of other people..[...].. So if you can work with professionals and other sufferers to develop something that can make people not have to go through that and feel like I felt, then you have just got to do it, you have just got to do it. I just find the whole group positive because it's actually making a change to what, to the service that is there at the minute, so from the charity's point of view because I speak to thousands of people with this condition who are absolutely desperate you can then turn round and say well you know in the future things will be there to help you, they are not there now, but they are working on them and they will be distributed as soon as they can, so it just gives people a bit more positivity about the future really."

5.3.3 Restitution

As mentioned in Section 5.1, the representatives viewed PPI as an opportunity to express their views and experiences to professionals outside of their normal clinical interactions. As well as seeing the potential benefits to the professionals and the research process, they

also personally valued this opportunity. The majority, if not all, of the representatives had experienced clinical interactions with medical professionals that had left them feeling *'deflated', 'devalued', 'disrespected' or 'dismissed'* (most often with General Practitioners or Consultants) with no direct opportunity for restitution. This was highlighted by James (SS1): *"Everyone in the group can come back with a story saying you know, well the doctor said this and really, it was rubbish."* From my interactions with the representatives I recognised that they saw having the opportunity to express their views directly to a professional as validating their knowledge and experience, compensating for a previous negative experience, regardless of it not having been with the same professional. I have labelled this benefit of PPI as *'restitution'*, as it appeared to allow for a rebalancing of the representatives' sense of self-worth.

5.3.4 The value of the research activity

While the motivations so far discussed could be viewed as not specific to a particular site and could have resulted in the representatives taking up any research-related PPI role, the representatives also discussed being motivated to take part in a given network or trial because they could see its individual value. As such they felt it was worth giving their time, effort and commitment to:

"If there is all this research around, and it's all ad hoc, it's not going anywhere, there is no, there is no focus for it is there at all, and.. nobody is saying well hang on a minute we have got this big gap here that, you know really we feel you could probably do a lot with this we just need somebody to have a look at it, unless the gaps are identified, they can't do it you know [identifying gaps in the research was the main task of the UKERN]." (Ron, UKERN)

"Everything that has been discussed at those meetings is, is important because there isn't anything at all so putting anything, however small or meagre in to the mix is going to help people because at the minute they have got nothing. ..[..].Because there is absolutely nothing at all for this condition, your expectations are get something out there and get it out there now. And that is exactly what, what the group is trying to do, and that is what we discussed at the meetings." (Moir, CS1)

5.3.5 Learning about epilepsy and epilepsy research

As outlined in Chapter 2 (see Section 2.6.2) past research suggests that representatives value gaining knowledge of their condition and of the research process, alongside gaining new skills (Minogue et al., 2005; Newell & South, 2009; O'Donnell & Entwistle, 2004; Rhodes et al., 2002). Indeed, the opportunity to learn more about epilepsy and epilepsy research was the personal benefit of PPI that representatives in my study most commonly identified. In addition to learning new information during the meetings, the representatives

also highlighted other components of the PPI process such as information from training events, attending academic conferences and having access to other sources of information such as newsletters and journals:

“The training was brilliant ..[.].I enjoyed it, it was a really good day, ((laughs)) and that's one of the most positive things about the whole thing I think was the training was ..the training was very good.” (Rose, UKERN)

“No it's changed I think, because I didn't really know what research properly was. I mean I suppose before I joined this, I just thought research was testing tablets an, and you know, didn't really know anything about it, so yes, it has changed a bit because I have seen a different side of it.” (Molly, SS1)

“I found that excellent actually, the conference I learnt so much, from that one day at the conference, I thought it was really good ..[.]. because you have got these very short term [20.10] prize winner you know, post-graduate research things which are actually quite accessible, I think, for patients you know for us, so again it is just nice to have to actually get involved in, in the field you know, just hearing things generally even if you can't take it in you get much more of a sense of what research is out there, what is current you know, what they think is really important that sort of thing just to switch you in a bit more I think.” (Katie, UKERN)

The UKERN representatives also viewed PPI as an opportunity to apply the research skills they already had but were unable to use in their current job roles:

“So for me it's quite important sort of professionally and personally that I still have a hand in research somewhere.” (Faye, UKERN)

“It will get my head back into academia to a degree, which that is where I started years ago, I was a potential PhD student, so I have always been sort of a bit that way inclined anyway. And I spent the last 30 odd years having nothing to do with it, so from a personal perspective, I like reading scientific stuff ..[.]. it's been good to read stuff again, because you don't read scientific papers in your day to day job, you don't and that, I have always, I have always found scientific papers interesting so it's good to be able to do that again.” (Ron, UKERN)

“My training involved having a sort of somewhat of a research background so just being able to kind of feel like oh yes I do remember a bit about that ((laughs)). You know I can, understand a little bit about research, is quite a nice thing as well.” (Rose, UKERN)

5.3.6 Social interaction

Another benefit of PPI for the representatives in my study which has previously been identified in the literature is the opportunity to meet others with a similar condition, providing new opportunities for peer support and exchange of information (Minogue et al., 2005; Rhodes et al., 2002). This appeared to be particularly true for Claire (CS1), as her condition was rare and she had limited opportunities to meet others with the same diagnosis:

“It is also nice to meet other patients that have actually erm, been diagnosed with erm, you know the same condition so you can also feel that you are not alone or going stark raving bonkers, which is also a good thing. So it forms friendships in that way.”

Katie (UKERN) also found the opportunity to compare her experiences with others with the same condition useful in identifying what was, and what was not, a result of her epilepsy, helping her develop her own understanding of the condition:

“Actually meeting people like Ron and Hazel and actually being able to discuss how it has affected us so from that point of view because I probably wouldn't have, if I hadn't done this I probably wouldn't have had that experience, well and meeting the people at various epilepsy events and doing the same sort of thing and just sort of saying oh yes well I feel like that you know I didn't realise that was part of you know, or potentially part of the epilepsy that sort of thing.”

Ron (UKERN) noted that his current PPI role not only allowed him to develop relationships with the other representatives, but also work with epilepsy professionals who he respected:

“It's like friendly people getting together and having a chat and both Katie and myself scenario at [event] last year and also Hazel and myself and Katie at [place], the meal the night before the meeting was really enjoyable and it was good. It's nice to see people, it's just nice to see people whose names you know..[.]... from a personal point of view that's really, really gratifying because I have had an interest in epilepsy for 30 years, 40 years, god knows 40 years, erm... so to actually get some of these guys, to get to meet some of these people who are, who are doing the stuff that they are doing is fantastic.”

While the networking and social support aspects of their PPI role did appear to be seen as a benefit by representatives, it did not seem to be one of the primary benefits of involvement as alluded to in the literature (Rhodes et al., 2002; Minogue, Boness, Brown, & Girdlestone, 2005). Rather it appeared to be a pleasant side effect. Lastly as stated by Ron above, representatives could find PP enjoyable and: “*quite exciting*” (Molly, SS1) activity to take part in.

5.4 Importance of confidence

As specified in Chapter 1, increased self-confidence has been identified as a potential benefit of PPI for the representatives. More specifically, representatives have reported increased confidence in their own capabilities and influence (Newell & South, 2009) and in giving presentations (Minogue, Boness, Brown, & Girdlestone, 2005). However, there is nothing in the literature that describes specifically what aspects of PPI give the representatives confidence in their knowledge or what affects their confidence in expressing their views in a given situation. The importance of confidence cannot be

overstated, since if representatives do not have the confidence to make their views known then, according to both their own and the professionals' definitions, they are not meaningfully involved.

This theme of confidence was woven throughout the representatives' discussions with me, at times being both a benefit and a challenge. Different components of the PPI experience appeared to positively or negatively influence their confidence. It was within this that the influences of the 'different approaches to implementing PPI' became particularly apparent. When discussing confidence, the representatives placed emphasis on their confidence in their own knowledge, the confidence to express their views and their confidence to disagree with professionals. In this section I will address each of these in turn, although it will be apparent that they were heavily interlaced with each other.

5.4.1 Confidence in the value of their own knowledge

As described in Section 5.1, the representatives were working from the assumption that they had knowledge that was valued by the professionals. It follows that if they had not had this underlying belief, then they would not have become representatives. The perception that their experiential knowledge was unique to them increased their confidence in their knowledge, as they argued no one knew more about their experience than they themselves. This was particularly important for Claire (CS1), who initially felt that her knowledge was not as valuable as Moira's (CS1):

"Because erm, Moira was there, she is you know, erm, in this trust [charity] so she knows a lot more about it so, it did feel at first that you know, what's the point in me actually being there, because this person knows, more about it than I do, so you know why should I erm, take part. Then you realise that you know, your opinion is, well as valid as what theirs is, you may have less experience but you have may have a, well, I would say I have a unique, erm perspective on certain things that they may not have. So, my involvement is, I feel you know quite as relevant as actually them because they do not have my point of view on my situation, so I can say, you know well you should include this, or, you know it's maybe not a good idea to phrase it in that way because, if they have got this issue or, a similar thing, may be offended by it."

In contrast, because a representative's knowledge was limited to their own experiences, this could also reduce their confidence, as they worried about representing people with epilepsy who might have had very different experiences (see Section 5.5.1). However, interacting with others with the same condition through their job roles, support groups, attendance at conferences or volunteer work, increased their confidence to represent others:

“I am fairly fortunate because I can bring it from two different aspects I can bring it from a personal level with my own daughter and dealing with her seizures, on a daily or a weekly basis and also seeing it from the other side where it's dealing with the general public, as a whole you know [in his role as a paramedic].” (Rick, UKERN)

“My experience of it and living with this condition and with the enormous amount of people that I meet and interact with that have got this condition, it is, you know gives me a lot of information, plus there is a huge resource and wealth out there, from the papers and yes you have to sit down with a medical paper and Wikipedia open and a dictionary open to try and figure out what it's all saying but I do and I get there. But if somebody asked me a question like at the medical conference we had last year, erm people were asking me questions and I would say well as a charity we do this, then you know, personally I think it's shocking that it's this bad.” (Jim, CS1)

Hazel noted that the more meetings she attended where she was unable to contribute, the less confident she felt and the more tokenistic she believed her involvement to be. Given that she was previously generally confident in her knowledge and in putting across her views; her experience highlights the potentially damaging effect of perceived tokenistic PPI on representatives' confidence:

“Well clearly we don't have the same knowledge do we ((laughs)) and some of the doctors are very... well they are excellent they are really good you know. Erm.. and yes experts in their field, I am quite impressed with them which is very reassuring. Er... but how we could... how we can contribute, is difficult to know really. I think it leaves me with that really, it leaves me with less confidence in how we can contribute but I am willing to continue trying.” (Hazel, UKERN)

As Hazel indicates, the value that the representatives perceived in their own knowledge was sometimes relative to their perceptions of the value of the professionals' knowledge. This concept was particularly well demonstrated by Katie (UKERN) who felt that while her knowledge was valuable, if given the choice, professionals would find comments from their colleagues more useful than comments from her:

“I did say a couple of things and it wasn't so much that I didn't have anything to say or... erm... was too scared to say it really, it was just that, there was such a short time after each speaker, that I felt that the professionals obviously should have a go first ..[..]. well I think the professionals are going to add more because they just know a lot more really erm... and I don't think... unless it has impinged on you personally it's very difficult to give a really erm... definitive first sort of you know, sort of first comment really. I erm... you know there were aspects that you could comment on but, as I say a lot of the times the professionals said it anyway, you know.”

Within my fieldnotes from the above day (a UKERN meeting where members presented research ideas to the network for constructive feedback), Katie explained to me that the difference between the situations when she chose to talk and when she did not, came from how passionate she felt about the topic and how important she felt it was in that context for the professionals to hear her point of view. Ron, who was at the same meeting,

expressed feeling in 'awe' of the professionals' knowledge and that he was less likely to be confident in his opinion in front of them. However, if the facilitator gave him the opportunity to voice his opinion then he would:

"These guys are like up there, aren't they, I mean in terms of the research and stuff they are doing, and while I will have a grasp of it from my professional qualification, erm... and so I know about the drugs and stuff like that,... they are dealing with brain chemistry on a day to day basis, and it's mind-blowing, brain chemistry is fantastic, I love it, but it's like it is really mind-blowing, no pun intended. So yes you tend to be a bit in awe of people like that. So if I am going to be invited to comment I have got to be pretty sure that what I am saying is reasonably ok, erm... so that's why I tend not to unless invited, if I am asked then yes I will give an opinion yes, every time. And I don't have a problem with giving an opinion, not at all, but when you are dealing with, when you are with a group of people who are obviously very knowledgeable and you are not, it takes quite a lot of guts to actually chip in... unless you have got a very valid point that you know is going to be a valid point and sometimes that happens it has not happened yet but, I am sure it will because the other thing is also true, and this is why PPI exists I guess, the science becomes so obviously important that you miss the point about the ethics and the morals and stuff." (Ron, UKERN)

Representatives also felt they gained external validation of their knowledge by being selected to take part as a representative. The formal application process provided validation for the UKERN representatives, as they felt they had to have the requisite knowledge and skills to successfully complete the application form and interviews. The more informal selection process, as used in the intervention study (CS1), also provided validation because if the recruiting professional did not believe them capable of contributing, representatives believed they would not have asked them to be involved in the first place:

"I know with this group, I think Isobelle [researcher and clinician] chose the people that were getting involved, well yes it was Isobelle that actually sent the letters out, so, I assume there is people that actually she had seen that actually were getting involved with this, so she knew they would be erm, good at this and wanting to get involved in the first place." (Claire, CS1)

5.4.2 Confidence to speak

When discussing their confidence to express their opinions, none of the representatives referred to written communication. Rather, the focus was on expressing their views verbally in the groups. Representatives whose professional roles involved presenting ideas and taking part in discussions reported higher initial confidence in expressing their views:

"I can be quite commanding when I need to be. So, if I am, I used to give lots of talks and such in my other jobs, so I just stand there it's like be quiet, listen this is what I have to tell you, you are here for information this is the information, and it's carer hat, but its crap I am sorry, you know so, I don't really have that much of an issue

with it. I can usually get my point across how it's needed to be put across so people understand, well hopefully help people understand it the best ((laughs))." (Jim, CS1)

Also, representatives with jobs that either had a health or research focus were more likely to feel confident in talking, as they felt they had a good understanding of the issues involved: *"I can read a protocol ...[..].I have always read protocols"* (Ron, UKERN). This was also true of representatives with other PPI experience. For example Molly (SS1), who reported feeling lacking in confidence prior to her involvement in the Comparator Epilepsy Network, spoke of how she was much more confident when she later became a breast cancer representative. One of the things that Molly felt had increased her confidence was the group dynamics of the patient research development group:

Chris "You are not made small, you know you are not made to look small as if you have said the wrong really.

Molly No,

Chris You know it's great.

Molly Because everybody is kind of in the same situation we have all got an illness in some kind of way, so they all kind of understand really if you say the wrong word it don't really matter."

Good group dynamics were particularly important for the representatives from the intervention study (CS1) and the comparator epilepsy network (SS1), as it made them feel confident enough to speak (see Section 5.5.3) and also, like the professionals, they noted that the more knowledge they had of other group members the more they could manage their own and other people's idiosyncrasies. The role of the facilitator was seen as key in establishing conducive group dynamics and ensuring representatives had the opportunity to speak. This is covered in more depth in 5.6.

5.4.3 Confidence to disagree with professionals

Having the confidence to disagree with or to challenge professionals was seen by representatives as more difficult than having the confidence to give positive or general opinions in group settings. A variety of reasons were given for this, including not knowing how the professionals would respond, feeling embarrassed, believing the professionals knew more about the topic area than they did and being worried about whether disagreeing with their doctors might affect the care they received. Again, the factors determining how confident representatives felt about challenging a professional included: the facilitator, the sense of rapport, feeling like they were being listened to, having confidence in what they were saying and past experience:

“I am thinking back relating to some of the, I suppose the different work I do with Age Concern. Erm, some of my professional work has taught me that I can speak out supposedly erm, top people you know, you don't have to be bowing and erm, you know cap in hand and erm, they are people, they are just people the same as you or I. Erm, I try not to erm, talk about something I know nothing about, but yes I think you challenge people as I did in my professional life, you know, I would be standing up talking to judges and giving my view or, you know, the defence, prosecution, solicitors etc., and to parole boards and I guess with my fencing too, erm, I am not the best fencer in the world but I stood up at World Championships and gave decisions.” (Hazel UKERN)

“You have to be kind of forthright and you have to be erm... able to speak what you think and not be [pause 04] not be, not feel pressurised or feel embarrassed by speaking to Consultants erm... I often find that, with working in a hospital environment, erm... a lot of people are a bit in awe of consultants we have had 16 years of dealing with consultants ((laughs)) and erm... they have all got their ideas, but they have got to get past, they have got to put them past and sell themselves to us, erm... what they are proposing to do with my daughter erm... so I don't hold consultants particularly in awe, that's as I say quite often I, when I speak to patients in the erm... in the clinics oh you can't say that to a consultant, I can't ask that, I say well why not? They are just human beings just like you and I, I said yes they have got more knowledge but I said if you have got questions, they need to be asked you have got to ask them, you cannot just erm... not ask because it's, because it's a consultant. You know and I often find that. Not only in the epilepsy clinics but also in the casualty kind of environment as well. I say if you have got questions ask, and but they won't, they are reluctant to ((laughs)).” (Rick, UKERN)

The ability to challenge the professionals was seen as particularly important: “*not to be irksome but because that is our role, that's what we are there for*” (Faye, UKERN). This role perception seems to contrast to that reported by a group of cancer representatives who viewed themselves as ‘friendly observers’, and did not see it as their place to challenge or question the ‘experts’, but rather to support them (Thompson et al, 2012).

5.5 Challenges

As evidenced in my literature review, while previously reported research has touched only lightly upon benefits of PPI to the representatives, even less is known about the challenges of their experiences. During my data collection for this study, I observed that the representatives seemed less comfortable discussing the challenges they experienced as part of their involvement, when compared to discussing the benefits. The ethnographic methodology I employed was useful when trying to understand these challenges, particularly those related to emotive and practical issues. From my observations it was apparent that the professionals were not always aware of the challenges the representatives were experiencing and this lack of awareness in turn negatively impacted

on their perceptions of the representatives. In this section, I give examples of such situations in relation to the challenges the representatives experienced while fulfilling their PPI roles.

5.5.1 Representatives as patients

One consistent challenge that the *patient* representatives had to contend with was that of the side effects of their epilepsy and their epilepsy medication. Unlike representatives with acute health conditions the representatives in this context still had epilepsy, a long-term and often poorly controlled condition. In addition, some of the representatives had comorbidities such as stroke, head injury, chronic pain, learning difficulties, depression and anxiety disorders. All of these had their own additional associated challenges.

Many of the patient representatives highlighted problems they had with their memory. This could result in multiple challenges in relation to the PPI role, including forgetting that they needed to do something or attend a meeting, forgetting what had happened in past meetings and problems when communicating. The representatives developed ways of working around these problems. These often involved drawing on support from the people around them:

“I have had a stroke and my memory is completely buggered, so actually remembering what people are saying can be erm, quite a challenge and also can get a bit annoyed because sometimes I just stop mid-sentence and forget what I am saying. But that’s just another aspect of it, so that’s why, when I am at the group, I try and if I can write down what people are saying or what people are asking me so then I have got a, a written record and I can look down and remember what I am talking about. But it’s good to actually involved because I think by now people know me and know that you know I have got a few issues, and if they need to just prod me in the right direction as it were, so that I can erm, carry on saying what I was saying, rather than not remembering.” (Claire, CS1)

“I have got a really bad memory because of my epilepsy, but I should have read over things before you came today.” (Molly, SS1)

“Let’s face it, I have had a head injury I forget. Molly is epileptic, she forgets, but if it’s really important Jess (NC) will text Molly or ring her you know, and we go ‘oh right we will go and check our e-mails’ so you know there is um, we are ill you know.” (Chris, SS1)

Another way that the representatives tried to minimise the impact of their memory and also concentration problems was to ensure that they did not get too tired, as tiredness could exacerbate these problems, potentially affecting their involvement in meetings and also having: “*a high personal cost*” (Faye, UKERN). So, for example, when traveling to meetings, the UKERN representatives made the decision to make the journey the evening

before the meeting to help ensure they were able to participate. However, regulations stipulated that they should not claim hotel costs, as theoretically they could all leave for the meeting after eight am and be home before nine pm the day the meeting was scheduled:

“Angela saying afterwards that we shouldn't have claimed for a night before because we should have been able to get up and back again for the meeting... for myself you know being a little bit older and Hazel is quite considerably older, that is quite an effort really ((laughs)) you know so, for that sort of distance but you know what the trains are like I mean I didn't get home until about 9 because it was a complete disaster going back.. I think we had all thought that it does help us.” (Katie, UKERN)

This issue of tiredness was important enough that two of the representatives were willing to pay for future accommodation themselves in order to travel in advance of meetings. However, it did leave a couple of the representatives feeling slightly resentful and undervalued:

“I personally didn't claim the money you were supposed to have erm... you know for going for the day, so another time I would just know to sort of pay for the hotel room myself and the meal instead of claiming that you know but it was a little bit sort of erm... ((laughs)) you know you didn't need to do this type of thing which is slightly off putting.” (Katie, UKERN)

It should also be noted that individuals with epilepsy commonly experience clinical depression and other mental health difficulties. As Sam (SS1) noted this could directly influence both their motivation and ability to get involved:

“It is a waste of time, I have been trying to get out of it, because I, I have become, unable to take part in a lot of things through, things like er (s2) speech there we are, my speech is affected, memory, depression, anxiety, and I go to a meeting these days, I used to be the chairman, I used to take part, I used to organise everything, now I kind of sit in the background and I don't, think my ideas have any value.”

Other medical issues that caused problems for the representatives were more person-specific, for example Faye (UKERN) also suffered from chronic pain and was unable to sit for long periods of time:

“I am not brilliant at sitting for long periods because it sparks off my chronic pain, so I can't do things like that of an evening [comment on participant information sheets], if I have spent hours in the chair, or if I have spent hours sat down during the day, so I just have to be a bit sensible about where I fit them.”

5.5.2 Practical issues

Throughout the data pertaining to the experiences of the representatives there were examples of practical challenges they encountered. For example, meetings of the comparator epilepsy network always happened in the evening, to allow those with work commitments to attend. However, this raised child-care difficulties for some:

“It’s in my diary to have gone tonight but my ex-wife has dropped my daughter on me this evening, but which I obviously don’t mind, but erm so can’t actually make it to the meetings.” (Paul, SS1)

The UKERN meetings took place during the working day which caused attendance problems for three of the representatives who had full-time jobs. Rose, for example, was unable to take the time off work to attend one of the face-to-face meetings. Both Faye and Rick made arrangements in their working day to take part in teleconferences, but on one occasion were unable participate due to pressing unexpected work demands:

“I missed one of them,.. I stupidly went to work and asked if I could do it as CPD time and erm... then a crisis call from one of my clients came in so I ended up having to go out and just missed it, literally missed it.” (Faye, UKERN)

“One of the meetings I was actually on duty on the day and had every intention of erm... staying on station and doing some paperwork until the time of the conference and then joining in the conference but erm... but my control room had other ideas. That’s why I came in really quite late, because I had a job to do.” (Rick, UKERN)

Unfortunately both of these events related to the same teleconference and neither individual was able to send their apologies due to the last minute nature of their work commitments. They also did not explain their absence to the professional lead after the meeting. This behaviour was seen as conflicting with academic norms and led some of the professional members of the group to question the representatives’ commitment and possible contribution:

“The second meeting was a telephone conference, one never turned up and the other turned up about 5 minutes towards the end of the meeting. Not sure that was particularly helpful, so I have yet to see evidence of what contribution they are going to make at this stage.” (Lee, CP)

In addition to causing discord between the professionals and the representatives, missing out on meetings also meant the representatives felt ‘out of the loop’ and had trouble completing some of the tasks they were allocated as they had not been present for explanations of what was involved.

Rick was meant to have designated research time within his job role and as such should not have needed to take annual leave to attend meetings. However, his line manager said that his participation in the UKERN had to occur in his own time. This disagreement led to him missing the first three meetings:

“I had problems at work with the, with my line manager erm... asking for, time to attend things like this erm... if those meetings were actually taking place on a... erm... on one of my shift days, I asked if I could take erm... like I didn't want to take annual leave, and I felt as if it was, because it was research orientated that my service would accept that fact and give me research time, which they have to give me. My line

manager took a really negative approach to this and said no, if you want to do things like that, it has to be, in your own time, so I was kind of a bit aggrieved because I thought well this is, this is not only benefitting me personally but I could pass this information on to my patients, erm... any information that I deemed relevant...[..]... I took the huff at because I thought well, they are wanting people to get involved in community type projects, I have to do it for to keep my registration, I am doing this off my own bat, but yet I am getting no support and no help from the service you see.” (Rick, UKERN)

He did not however, explain this to the CSG lead or respond to any emails from the network for approximately six months.

Other practical difficulties representatives experienced included problems concerning payment, information technology problems (such as websites being down) and difficulties using academic search engines. Resolving these issues was time consuming and frustrating for the representatives:

“If you say that you are willing to offer them money for coming, make sure you are able to give them money for coming, erm because at the moment we are still waiting, from the last lot to be paid and it seems to be a bit of a farce that we are having to chase up to be paid for it, erm and I don’t think it’s right that we should be put in that position. So either give people money for coming or don’t erm, don’t make it difficult in that way because that could, it doesn’t put me and Moira off but it could put other people off especially if people are taking time out from work and such to do that.” (Jim, CS1)

“I was unlucky or I am just thick ((laughs)) I really struggled with this in that I couldn’t access the erm.. the original documents. .. we were advised to look in one particular website, PubMed, erm... which I went on and I spent hours and hours trying to get on, as you probably know there are different, there are different PubMeds, there is an American PubMed as well which it took me a while to realise that.. er... I did eventually get access to er... the correct PubMed and as I say I spent a long time doing it, you know I would say several hours, over 6, or 7 or 8 hours even I would say in total. When I eventually did get on the right PubMed it is obvious that the reason I wasn’t getting any response because there wasn’t any publication ((laughs)) I found it really frustrating.” (Ron, UKERN)

5.5.4 The problem of ‘jargon’

In Section 5.1.1, I explained that the general consensus among representatives was that professionals have a tendency to talk in a way that ‘normal’ people do not understand. It is therefore not surprising that representatives reported experiencing difficulties understanding some of the language used in meetings and research documents. This was a problem that all representatives experienced, even those with a health or research training:

“I went over to one meeting and realised I hadn’t a clue what anybody was talking about because they all use these strangest anagrams and acronyms or whatever, it is, and I asked a few questions, just made me feel dumb you know.” (Sam, SS1)

“People were firing stuff in, ideas and it was all going over my head, it really was going over my head and some of it was due to language they were using and the acronyms that people use and I am as guilty of that with my own field as anybody else but it's assumed that you know what a PCL whatever a PCL is, ((laughs)) and a PPR for that matter you know and erm... so these things flying about don't help.”
(Ron, UKERN)

As Rose (UKERN) highlighted, this might not necessarily have been a representative specific challenge, as she observed that some of the professional members in her group might have had difficulty understanding some of the projects as well:

Rose “I found that easier to answer for the non-basic science stuff I don't think I would have been able to answer it ((laughs)) for the basic science at all.

Beth *I think there is only about 1% of the population that could.*

Rose Well yes, basic scientists probably. ((laughs)) So erm... but I mean you know that is not to say we shouldn't be looking at it but it makes it harder to look at that kind of stuff.”

I also observed that Katie took a glossary of research and epilepsy words with her to a few of the UKERN meetings. When I asked her about the glossary she said: “*it was certainly helpful because you could sort of glance down it erm... from time to time*” (Katie, UKERN). Katie suggested that an updatable glossary might be useful for when new terms needed to be included. Representatives felt that they did not need to understand all of the jargon (their term) used to make a meaningful input into discussions; rather the challenge was knowing when they did and when they did not need to understand the detail.

5.5.5 Is PPI worth the time?

As discussed in Section 4.4.3 and in the literature review (see Section 2.6.1) the amount of time PPI takes was seen as one of the main challenges for the professionals. This also appeared to be true for the representatives. In line with the professionals' experiences, PPI was reported to take up a substantial amount of the representatives' time. Not only did they need to take time out of their work or private lives to attend meetings (see Section 5.5.2) but it also took time to look at the relevant documents, prepare for meetings (for example reading the INVOLVE guidelines for representatives), attend training events, complete the application process (UKERN), travel to meetings and do background reading about the topic. Some of the representatives also found managing their time between their PPI role and other commitments challenging:

“You go through that process where you spend a lot of time thinking about filling in applications, going up for an interview, and then actually wanting to get started.”
(Hazel, UKERN)

“Organising your time so that you can, you can do it you know because you have other commitments and at the moment you don’t really know when erm, it’s going to be you know sort of, it will land on your doorstep or whatever, you know so and how much time that it’s then going to take to do that, so it is time management as well. Erm, [05] yes I would say that’s my, for me that’s the main challenge.” (Katie, UKERN)

In addition to taking time, the representatives noted that they *needed* time to look at and understand research documents to formulate opinions. As such they might need a longer turnaround time than professionals were used to offering:

“When do we get the stuff to read, and how much time do we get to read it, erm before the conference or whatever it might be, that sort, that sort of detail it needed...[..]. It was important we had time to do more research and organise our thoughts and formulate any queries we might have..[..]. I only got this document yesterday so I am feeling a bit unprepared for the meeting this afternoon.” (Ron, UKERN)

They might also need time within meetings to formulate their answers:

“Getting your thoughts together coherently enough in the time I think I would feel a bit, being part of the general audience was ok but I, I did feel being part of erm... being part of the panel I would have found it a bit pressured to get my thoughts together I think if you know what I mean. I think this why I suggested you know perhaps jotting down comments to submit later.” (Katie, UKERN)

The representatives also drew attention to how they needed time to establish rapport with the professionals and other representatives in the group, in order to not just understand the research but also to adjust to group dynamics and feel confident in expressing their opinions:

“There is a catch 22 because if you are only meeting once some people may want to get involved more than if you are meeting a couple of times ...But of course, you don’t get time to actually get to know everybody.” (Claire, CS1)

This need for more time could potentially conflict with the professionals’ wish to keep the research process as short as possible and the academic convention of quick turnaround times, e.g. sending out documents for meetings the day before they take place.

The length of time research took was also challenging for the representatives. While they accepted that the research process can be a lengthy one and were willing to make on-going commitments over months or years, at the same time they found it frustrating and disappointing when the amount of expected involvement did not match the actual amount of involvement:

“Because it’s a new concept, erm.... It’s going to take time so, it is frustrating in the sense that... it’s slow really, because I ran a business you see and you don’t get time ((laughs)) you know you don’t usually get time you have just got to do things and then set them in motion and that’s that. But erm... I do appreciate that people are

doing other things you know so it is obvious that while it's important it's not a priority number 1 for most people. So it will take time. So I am not, I don't have any particular problem with the speed of it it's just that, it is new to me." (Ron, UKERN)

"If you have got people who are sort of wanting to be enthusiastic and erm... involved and I guess it could be then a bit off putting if it's taking a long time to set it up really.I suppose people just might feel a bit disappointed that it's kind of not what they thought it was going to be." (Rose, UKERN)

"We make progress but maybe we take 3 steps forward and maybe one back then, and so it's slow progress but it's, it's bound to be isn't it, especially the first couple of years, as we get to know each other and get to know what is happening in the whole area of research in epilepsy." (Jill, SS1)

This time cost to the representatives seemed to be the underlying reason for their emphasis on meaningful involvement. If they believed they could have an input, could see some concrete sign of being listened to or outputs from their efforts or could see some personal benefits, then PPI was worth their time. If they could not see any meaningful benefits of their involvement they 'lost interest' in the research activity which, as noted in section 5.3.1, was the primary motivation for involvement. As described in Chapter 2, UKERN held their meetings during an academic conference that professional members were already attending. This limited the time commitment for the professionals, but meant the representatives had to travel specifically for the network meeting. It was therefore more disappointing for them and significantly more a 'waste of time' if a meeting turned out to be short or non-productive:

"I was a little bit disappointed, we were literally in the meeting for 15 minutes and they were just going through the list of erm... research and it was only doctors that could you know, professional people that could actually contribute, we could contribute nothing at all to that and erm... it just seemed a big waste of time really ((laughs)) and that they probably should have realised that and sort of said you know just leave it really. I mean we tried to make it more, erm... beneficial for ourselves [travelled 2 hours both ways to get there] by going to the morning in the conference that was sort of an added thing but if it was not for that... we should have realised that it was going to be a complete waste of time for us really." (Katie, UKERN)

5.5.6 Issues of 'representativeness'

As described in Chapter 4 (see Section 4.4.3), some of the professionals worried about selecting representatives who were *really* representative of the epilepsy community. This was a worry also shared by some of the representatives:

"I don't think there is a big enough cross section of erm, sufferers going and carers going. Carers tend to be partners or parents, erm, sufferers tend to be because of the, the way the condition is mainly female but I think it would benefit from maybe a male sufferer a young sufferer, an old sufferer erm, and people from different

backgrounds so, erm, you know somebody from a, I don't know how really, how to put it other than different backgrounds really." (Jim, CS1)

"I understand from my point of view, from my daughter's point of view or the people I have been in contact with, but there is all sorts, you know epilepsy is so wide, it's erm, I have limited, I have had limited contact with people with disabilities etc., and I know that my knowledge of that is quite small really. At least I perceive it to be. [laughs] it might not be so small compared to some other people." (Hazel, UKERN)

Some of the representatives saw the role as carrying a responsibility for the epilepsy community as a whole and worried about how they could represent others when they only had their own experience on which to make judgements:

"Because you are not getting everybody's view, you are getting that person's view. And that person has to be careful about how they speak for the masses, and to have an understanding about how they have a very important role but it might not have, it might not be their view point they have to think about how it's other people's views as well they are representing. I think it's a, I do think that it's quite an honourable position to be, erm, a representative in form or another but it carries a huge weight and I think that is a sometimes undervalued aspect to it. And the weight is that you have to try and remember that you are not just speaking for yourself." (Faye, UKERN)

One way the representatives appeared to reconcile this worry was to comment from 'their experience' or from 'their point of view'. As such they were able to feel that they were not potentially misrepresenting the views of others. Another way to address this worry was to interact with the wider community outside of the research context and informally collate others' views so they could feel more confident in stating 'we think'.

Alongside worrying about whether they were representative in terms of epilepsy experience, four of the UKERN representatives were worried that they were not representative of the wider epilepsy community due to their medical or research background. They believed that they might be less able to give a non-professional perspective as they saw themselves as 'more professional' than non-professional. Overall, however, they seemed to view their professional knowledge as a benefit and not a hindrance, since it allowed them a greater understanding of the context of the research and, as their training was different to the professionals, it provided them with another set of knowledge to contribute. While they felt they could separate out what was their representative perspective and what was their professional perspective it was something that they felt they had to be consciously aware of. Ron described his experience of this issue in the most depth:

"I try and look at it from a purely lay perspective, erm... but I can't entirely do that you know...[...]. it's difficult at times. Erm... because inevitably, instinctively, as soon as I see something on paper I analyse it, it's part of my job erm... I should be doing

that but not in a professional sense. ..if you are not careful you get sucked into the actual mechanics of the trial itself rather than the objectives of the trial and that's, that will get easier and to take an holistic view of the trial at the moment is quite difficult because I am not too sure whether we are actually at that point or not yet, I think we are still trying to identify gaps and also where treatment is good, where research is good and to that end you do need to have some technical knowledge. So I find that really useful. So it's not all a bad thing, and erm... so some of the scientific stuff as I say I can't understand it, some of it I can so that's helpful. Erm... whether it's a particular problem, which is the question you asked it probably is yes? But only because I am aware of it and perhaps in that sense it's not, but I do tend to read it on two levels, I do tend to read stuff on two levels and erm... I mean it's not always possible to read it in a lay level because it's scientific, at which point as a lay person I should be thinking I don't understand that, and that is perfectly ok I would imagine but I don't I try and understand it ((laughs)) and that's where it becomes a bit of a problem. So erm... the word problem I am not sure is the right word I don't think it is a problem because it's not been so far but it is certainly something I am aware of.... I have worked it out and I can now work with it, recognising as I do that I will always inevitably look at stuff from a scientific view point because that's what I am trained to do, now I need to look at it again you know ((laughs)) which I am quite happy to do.” (Ron, UKERN)

Thompson et al (2012), found that representatives drew on their relevant expertise (career, education or training) to legitimise their position as a credible participants within a cancer setting. In contrast the representatives within the UKERN appeared worried that it reduced their legitimacy as a ‘real’ representative.

5.5.7 Emotionally challenging aspects of PPI

Throughout this chapter the emotional effects of PPI on the representatives have been raised, for example issues of confidence, enjoyment and frustration. Building on this, the potentially adverse emotional impacts of PPI can be seen as challenging to the representatives in their own right.

Representatives repeatedly stated that initially their role in the PPI process made them feel ‘nervous’ and they worried about ‘looking stupid or silly’. Their nervousness seemed to arise from finding themselves in a social situation where they were uncertain how the professionals and other representatives would respond to them, rather than as a consequence of being involved in the research process per se:

“The first meeting, yes I was very nervous about the people. Erm, that was actually in the group because I was very nervous about meeting anybody I didn’t know at that time...[.]. , you know you never know what, how people may react to different situations so, if you have got many conditions like I have, then it can be a challenge meeting new people.” (Claire, CS1)

“No when I first went in, actually I was quite scared. I remember going there thinking oh my God, what are we going in here to, were not good enough for this you know because we are no doctors or anything, but then when you actually go into the meeting and you sit down and you start to talk you realise everybody is just a person, and um, we were all treated the same so it was really lovely. We were made to feel at home and explained what it was about and it is really nice.” (Molly, SS1)

Unsurprisingly, this nervousness was most challenging for less confident representatives; however, it was something that all the representatives expressed feeling. Linked to this, representatives worried about being judged by the rest of the group and the majority of representatives (regardless of background or level of confidence) expressed feeling apprehensive about being considered silly, or stupid:

“That's just natural I mean that's because you don't want to look stupid it's as simple as that. I mean I think I know what I am talking about, but these guys are like up here aren't they, I mean in terms of the research and stuff they are doing, these guys... they are dealing with brain chemistry on a day to day basis, and it's mind-blowing, brain chemistry is fantastic I love it, but it's like it is really mind-blowing, no pun intended. So yes you tend to be a bit in awe of people like that. So if I am going to be invited to comment I have got to be pretty sure that what I am saying is reasonably ok, erm... so that's why I tend not to unless invited, if I am asked then yes I will give an opinion yes, every time. And I don't have a problem with give an opinion not at all but when you are dealing with, when you are with a group of people who are obviously very knowledgeable and you are not, it takes quite a lot of guts to actually chip in... unless you have got a very valid point that you know is going to be a valid point.” (Ron, UKERN)

Beth “You said that with your idea you told Jess and Tom before you told the group,

Molly Yes

Beth Why do you think that is, why do you think you...

Molly I suppose I felt that it wasn't good enough, I felt shall uum, I tell them, shan't I tell them and I didn't really want to go to the whole of the group and tell them in case they would say oh no it's been done before, or, or they would say oh no it's silly, or they would laugh or you know I felt a bit insecure about reading something out um, and them turning it down, so I was a bit nervous about it so I thought I would prefer to mention it to them first and then when they said it was a good idea they said write it all down and then put it to the group and er yes, so I was really nervous about coming forward, with it I suppose in case it would be I suppose rejected but a lot of people, aren't nervous like me, um, er about getting I suppose knocked back you know, but I think it's partly maybe that could be because of my epilepsy with my schooling and that, because I have had a lot of knock backs over the years, so it's a bit of a lack of confidence I think with me. So I think I was just happier approaching them first before putting it forward yes.” (SS1)

As Ron noted, the worry about looking stupid is particularly relevant as it might prevent representatives from voicing their opinions. As such the value of a form of PPI that involved

multiple meetings with a consistent membership was once again acknowledged, as the first meeting with new people was the most nerve-wracking and familiarity with the group helped increase confidence to speak (see Section 5.4.2).

Furthermore, and potentially more importantly, the representatives within this study were involved as a result of their personal experiences related to epilepsy. Because of this they could find discussions around epilepsy highly emotive. In comparison to the issue of nervousness about voicing opinions, none of the representatives identified the personal emotional effects of the content of the research in their interviews. However, that this was an issue was apparent within my fieldnotes, the clearest example occurring at the ILAE conference a few hours before the UKERN representatives attended their first meeting. Kate and Hazel had spent the morning listening to conference presentations:

“The first session was the prize winners which meant the presentation of three essays/ bits of research, then a ‘case that changed your practice’. These were presented clearly. After the session both Katie and Hazel said that they had found listening to the talks very emotional especially the ones that applied to themselves, or as in Hazel’s case, her daughter. They seemed to have run it through their own experience saying things such as ‘my daughter also has diabetes’, and talking about their own memory problems. (Something covered in one of the talks). They even said to me, that this is something to include in your side effects of PPI- the emotional effect of listening to research. Katie during the questions at the end of the memory presentation put her hand up and made a comment that as a person suffering from the disorder just mentioned, information on memory loss would be really useful in the early stages (not certain she said early stages) even if they could not do anything about it. I remember thinking at the time that if she was willing to talk in a large majestic ballroom full of people with a microphone- something I personally would have been very reluctant to do, then she will probably not have a problem talking in the CSG meetings.” (Extract from fieldnotes at the ILAE conference)

What seemed particularly pertinent to me was this idea that they would have to ‘have run it through their own experience’ in order to make a judgment. Essentially this required them to relive potentially upsetting aspects of their past. Neither Katie nor Hazel raised this challenge spontaneously in subsequent interviews. When I asked them directly about this incident, Hazel reflected:

“Being involved in anything to do with epilepsy erm, can be emotionally draining for me because, there is a lot of emotional content there for me. I am retired now, but I don’t think I would emotionally be able to deal with working full time in it, so I think that’s why, in the early years, that I didn’t get involved at all. Erm, too close to me emotionally because of my own circumstances and my daughter’s I think.”

This issue, perhaps more than any other presented in this chapter, helps to demonstrate the benefit of the ethnographic methodology I adopted, as it appears this emotionally disrupting component of PPI was not something easily articulated in interviews, but it was

clear within my observations that it had an marked impact on representatives' experiences. It also needs to be acknowledged that some of the representatives had family members who had died as a result of epilepsy. As well as being personally upsetting, hearing about their experiences affected other members of the group also.

5.6 The importance of the facilitator

Besides consistency in group membership one factor the representatives identified as helping them overcome their general nervousness and the worry of looking 'stupid' was the influence of the group facilitator, who set the tone of the group interactions:

Chris "And even if you say the wrong thing

Molly *It doesn't really matter does it*

Chris You are not made small, you know you are not made to look small as if you have said the wrong really.

Molly *No,*

Chris You know it's great." (SS1)

The importance of the facilitator resonated throughout the interviews with the representatives, for example how they managed group dynamics and created space for individuals to contribute could increase their confidence to speak in the group setting:

"If I am going to be invited to comment I have got to be pretty sure that what I am saying is reasonably ok, erm... so that's why I tend not to unless invited, if I am asked then yes I will give an opinion yes, every time." (Ron, UKERN)

"If you have got a smaller group like you have got, I don't know 6 / 8 / 10 people then it's a bit of a better dynamic because you have, you have, you have got a chance to actually erm, give your point of view and I think one thing Rachel does she actually erm, she actually asks you, if she notices that you haven't said anything she actually says well have you got anything to actually comment on this, You might not have, but you might also feel too embarrassed to actually make that comment, and you know sometimes when people does that, it, it can make you want to speak out, or can actually make you feel, why is everybody looking at me." (Claire, CS1)

Hewlett et al (2006) support this observation, by stressing that good chairing of a meeting is a key factor in enabling representatives to contribute: "*particularly initially when partners may require additional support, such as being specifically asked for their experiences to enable them to enter the discussion*"(P. 677).

The facilitator also needed to be able to control the group, working around strong personalities while being sensitive to emotive issues, staying on topic while not shutting down conversation:

James “There is always a danger that that group will be a moaning group and er, I think Jess and Tom are aware of that. I mean there are tendencies I think, um you know you saw last night that you know, certain members of the group can be carried away with their personal problems, so I mean that’s fair enough.

Jill *And it sort of repeats itself every meeting doesn’t it. Sometimes I feel that, we and Jess must feel that we could be making more progress, than we are,*

James But on the other hand these people are suffering you know,

Jill *Yeh they are suffering and I think the way Jess and Tom deal with them and allow them to, to speak every you know, all the time is good for the patients isn’t it.” (SS1)*

“Some people who are ill are not, ur, don’t know when to stop talking or talking about the wrong things urm, could possibly upset somebody just by saying the wrong thing. Erm, and you know whoever is in charge of the meeting has got to handle it with kid gloves sometimes and be quite clever the way they er run the meeting you know.” (Chris, CS1)

The UKERN representatives emphasised that a good facilitator was vital during telephone conferences where the visual clues they would normally draw on were missing:

“Francis is good, she chairs those well in our group erm.... and it's quite easy to kind of you know I think, I have never done anything like that before you think oh it will be a bit weird doing it all over the phone but it's actually quite sort of relatively easy to follow what is going on.” (Rose, UKERN)

In Section 4.5.4, I reported on Nick’s reflection that he felt his clinical relationship with the representatives might have an inhibiting effect on the discussions. This was also commented on by the representatives themselves (and documented in my fieldnotes). They suggested that this might be due to fear of the comments made within the meeting affecting their clinical relationship outside of the meeting:

“You can sometimes think well I don’t want to say too much because I don’t want to upset the patient relationship with your GP, or your consultant or whatever so I think some people can be a little bit cagey, sometimes, I have looked round that meeting, that the NEST meeting and I have thought are you holding back, you know when you can tell in someone’s body language they want to say something but can’t, I have often thought is that because you are a bit anxious about there is a consultant there who is listening to everything you are saying and might say you know, might be a bit upset if you say the wrong thing, but you know I think it is more important that they hear the truth.” (Moir, CS1)

Also, they were used being in a clinical relationship with Nick and as such to interacting with him in a particular way. It is possible that this pre-established relationship was a factor in their inhibitions, independent of potential future consequences.

The representatives generally felt that responsibility lay with the professionals to make PPI work and enable useful interactions:

- Faye “He should hear what you have to say, that is the point.
- Beth *I also interviewed the researcher and he was going, no, I want to know what they have to say that is why I am asking them.*
- Faye Isn't that interesting that he hadn't communicated that enough for her to get that.
- Beth Yes
- Faye Because somewhere along the line he hasn't given her the signals that that is ok.
- Beth *He was like, no, I want to know what they want to say I can talk to professionals by walking down the corridor, I want to know what these people think.*
- Faye So how has he not, how have they not managed to explain that I wonder, fascinating that isn't it?” (UKERN)

“Perhaps it's, that professionals need to erm... you know... kind of manage their own feelings about it [being criticised] better really because you are not going to avoid it and if you truly do want patients involved and people involved then that is one of the things you are going to have to deal with isn't it and otherwise you will just, you know if you just want all the ones that say nice things ((laughs)) and don't annoy you, and do as you say then that's not really how it works I don't think...[..]. they [professionals'] get defensive rather than sort of think about how they can help that person understand this is how we do a meeting, erm... yes I think it's difficult. I think yes, I think probably you know there needs to be a lot of preparation, work and support and, and you know just maybe sort of talking to the person about those issues rather than just moaning about them. ((laughs)).” (Rose, UKERN)

Lastly, it should be noted that representatives might not see the impacts of their involvement, should these impacts occur outside of the meetings. It was often the communication with professionals (and more specifically, with the facilitator) and the feedback representatives received that indicated to them whether they were being actively listened to and if their contributions were having an impact. It was this knowledge that helped representatives to judge if their involvement was meaningful.

5.7 Discussion

In this chapter I have described my analysis of the experiences of the patient and public representatives within my research sites and how they conceptualised PPI. Representatives viewed the primary function of PPI as being for professionals to get a '*different point of view*' or more specifically a '*patient's perspective*'. This different point of view was seen by the representatives as resulting from their experiential knowledge about epilepsy but also,

in some cases, from the perspective of a non-‘professionally’ trained person. Building on this, they viewed ‘meaningful’ involvement as having the opportunity to give their opinion and have it listened to in situations where their contributions *could* potentially have an impact. To an extent, whether or not they actually *did* have an impact was secondary.

Representatives felt that PPI could help improve the research process, resulting in improved recruitment and dissemination. They also identified personal benefits that they had experienced as part of their involvement that overlapped heavily with their original motivations for involvement in research. These included: personal interest, making a difference, restitution, the value of the research, learning about epilepsy and epilepsy research and social interactions. Consistent with their understanding of ‘meaningful’ PPI the representatives appeared to be primarily motivated by pragmatic or consequentialist reasons rather than moral or political ones.

Representatives also articulated experiencing six main challenges as part of their PPI role. This included, dealing with side effects from their illness, practical issues, the problem of jargon, time commitments, worries about representativeness and the emotional effect of being involved in research linked to a condition of which they had personal experience. My review of the literature suggests that majority of these challenges are not currently articulated within it.

This chapter draws attention to two important aspects of the PPI process; the role of the facilitator and the level of confidence the representatives have in their own knowledge, to speak in groups and to disagree with the professionals. To an extent, these factors seem to link back to the representatives’ perception of underlining power differences between themselves and the professionals. This effect of perceived ‘power’ distribution is discussed in more depth in the discussion chapter.

Chapter 6. Further consideration of key findings about process and perceptions

6.1 Introduction

In the preceding results chapters I have offered a detailed account of the PPI implementation process undertaken within each of my sites (Chapter 3) and the experiences and perceptions of the professionals (Chapter 4) and representatives (Chapter 5) involved. In this chapter I will consider these findings from the previous chapters at a more conceptual level and to address objective 4: *'to compare different approaches of implementing PPI, by contrasting the experiences of the professionals and representatives across the different research sites'*. As detailed in section 2.8.1 this meta-analysis was achieved as part of my thematic analysis process, drawing on the premise of the hermeneutic circle. As I gained insights from consideration of the three sub-component data sources I then used them to examine my data as a whole. As I developed my understanding of PPI as a whole this information was then evaluated and re-examined within the sub-component data sets, which in turn fed into my understanding of the whole. This process led me to focus on how both representatives and professionals classified the different types of PPI, identifying the strengths and limitations of the different PPI approaches adopted by each of the sites. I then looked at these strengths and limitations on a more generic level, proposing seven factors of 'quality' PPI against which to evaluate my sites. Lastly I drew on the data to set out what I understand to be the fundamental characteristics of 'meaningful' PPI.

6.2 Typology of PPI

Throughout my data analysis it became apparent that neither the professionals (see Section 4.3) nor the representatives (see Section 5.2) described or conceptualised PPI in terms of the currently available models of involvement (see Section 1.4.1); and having explored the PPI processes implemented in each site (see Chapter 3), I reached the conclusion that it was not appropriate or desirable to try to classify the type of PPI being implemented within my sites using these traditional PPI models (see Section 1.4.1). My participants placed little or no emphasis on classifying PPI by power over outcome and in addition the traditional models seemed to offer an over-simplification of the different 'types' of PPI implemented within my sites. Drawing specifically on the 'influencing factors' (see Section 3.6) and key

process points identified during Chapter 3, in conjunction with the rest of my data analysis, I have therefore developed my own typology to describe PPI. Within this typology I identify four key dimensions along which, I would argue, PPI can be considered:

1. Personal-Proximal-Distal positionality
2. Partnership-Advisory role within PPI process
3. Integrated- Separated organisation of PPI activity
4. Targeted - Generic nature of PPI

Each of these dimensions is detailed in Table 10. Similar to the dimensions described in Gibson et al's (2012) model of involvement, these four dimensions are intended to be conceptualised as a non-static continuum rather than a dichotomy; over the course of the PPI development process the position on any dimension may change.

Based on this typology, my epilepsy specific sites would be labelled as follows:

Main site, UKERN: integrated, personal/proximal, generic, partnership

- Integrated: the representatives were part of the same group as the professionals
- Personal/proximal: representatives were chosen because they had experience of the condition either personally or through a close friend/ family member
- Generic: once representatives were part of the network, they could, at least in theory, take part in all network activities
- Partnership: representatives were presented as equal stakeholders in the network.

SS1, the Comparator Epilepsy Network: Separate, personal/proximal, generic, partnership

- Separate: representatives have their own group separate from the professionals
- Personal/proximal: had experience of the condition either personally or through a close friend/ family member
- Generic: representatives were not included to achieve a specific goal; rather they decided their own purpose.
- Partnership: while part of the representatives group's function was to provide advice to the rest of the network they also shaped the network and had developed their own research suggestions.

CS1, Intervention Study: Separate, personal/proximal, targeted, advisory

- Separate: representatives met separately from the main group of professionals.
- Personal/proximal: representatives were selected because they had experience of the condition either personally or through a close family member.
- Targeted: representatives were present to comment on specific aspects of the research process.
- Advisory: representatives were included to provide feedback only.

Table 10: Typology of key dimensions of PPI

Dimension 1: Personal, proximal, distal involvement	
<i>Personal</i>	The representative(s) have a 'lived experience' of the condition themselves. For example in CS2 (clinical trial), the professionals were concerned with accessing the opinions of women with epilepsy who were, or who had been, pregnant.
<i>Proximal</i>	The representatives(s) have experience of the condition through an affected close family member or friend. For example in SS1 (comparator epilepsy network), representatives were not only those with <i>personal</i> experience of having epilepsy, but also family members of people with epilepsy and professionals working with people with epilepsy.
<i>Distal</i>	The representative(s) have no experience of the condition either personally or through a family member or friend, but are present to give a generic 'non-professional' or 'public' opinion.
Dimension 2: Partnership- advisory involvement	
<i>Partnership</i>	Representatives are equal stakeholders in the research process. For example in SS1 (comparator epilepsy network) the representatives worked with the professionals to determine the purpose of the group; and in UKERN representatives had the same collaborative role as professionals.
<i>Advisory</i>	Representatives are asked to provide feedback on discrete areas identified by the professionals. For example in CS1 (intervention study) the representatives were asked their opinion on the study design and associated documents.
Dimension 3: Integrated- separate involvement	
<i>Integrated</i>	Representatives are physically situated with the professionals. For example in UKERN and in CS2 (clinical trial), the representatives were members of the research groups.
<i>Separate</i>	Representatives are detached from the professionals. For example in SS1 (comparator epilepsy network) and CS2 (clinical trial) the representatives met independently of the professionals.
Dimension 4: Targeted - generic involvement	
<i>Targeted</i>	The representative(s) are present to achieve set tasks or goals. For example in CS2 (clinical trial) they were present to give feedback on specific issues such participant information sheets and the website.
<i>Generic</i>	Representatives are involved in the whole process. For example in SS1 (comparator epilepsy network), where they determined their own purpose and how they wished to function.

CS2, Clinical Trial: Separate/integrated, personal, targeted, advisory

- Separate/ integrated: During the feasibility study representatives were independent of the research team, however through the Steering Group and Data Management groups they were integrated with other stakeholders.
- Personal: representatives had to have had personal experience of the condition (pregnant female with epilepsy).
- Targeted: representatives in each stage of the PPI process were present for a specific aim.
- Advisory: representatives provided feedback and advice to the research team.

Before I discuss the application of the typology (see section 6.6), I am first going to describe the findings of the analysis of the strengths and limitations of each of the approaches to PPI implemented within my sites.

6.3 Strengths and limitations of four PPI approaches

Barber, Boote and Cooper (2007) noted a lack of comparative studies focusing on different approaches to PPI and how this has limited the ability of PPI research to evaluate the different methods in relation to each other. This prevents both professionals and representatives from making informed decisions about their involvement in the PPI process. I attribute this lack of comparative studies to three key factors. Firstly, 'models of involvement' that classify level of involvement by power over outcome intrinsically imply that the higher levels are 'better' than the lower levels (see Section 1.4.1). Secondly, the existence of strong moral and ethical arguments in support of PPI could be a direct deterrent to scientific challenge and scrutiny (Salmon & Young, 2005). Because PPI was originally morally and politically motivated, researchers may be reluctant to examine it critically, particularly at the present time, as it is seen currently as something that must occur, regardless of the outcome. Thirdly, some components of the PPI process are clinical condition-specific and it may be problematic to compare approaches of PPI across different conditions. For example, issues surrounding involving someone in a wheelchair may differ substantially to those of involving someone who has had a stroke. The research reported in this thesis provided an opportunity to compare different approaches to PPI within a single condition, epilepsy, thus removing the third factor from consideration.

Tables 11 and 12 give a brief summary of the key components of the approach to PPI adopted by each site and detail the strengths and limitations of that approach as identified by both my research participants and myself through the analysis process. The strengths and limitations that were raised directly by the participants and explored specifically in other chapters are designated by the Section number in which they were discussed. Those derived indirectly and attributable to my own interpretation of the data are denoted by my initials (ED). As explained in Chapters 2 and 3, the UK topic-specific research networks (SS2) were approached differently to the other sites. The aim of including them as a research site was to provide an overview of the experiences and perceptions of the key issues around PPI among Network leads, who already had considerable experience of implementing PPI, rather than to generate a detailed understanding of the particular PPI processes they had

implemented. Given this and that each of the topic-specific research networks had implemented a range of PPI approaches, I chose not to include them in this comparison and confine my analysis to the epilepsy research sites only.

It was apparent that the individuals involved in developing and implementing PPI at each site felt that their particular approach to PPI was the most appropriate one for them. This took into account the original motivation(s) for PPI, the aims of the research and preconceptions about representatives, 'representativeness' and what counts as a 'valid' opportunity for representatives to express their views (see Sections 6.5 & 3.6). For example, the professionals implementing PPI in the intervention study (CS1) did not consider having representatives on their steering group, which they thought would be 'tokenistic', as they believed representatives would struggle to contribute. In comparison, the professionals in the clinical trial (CS2) felt that as long as the representatives were 'listened to', having them present at the steering group and data monitoring committees meant that they had meaningful PPI.

As detailed in Tables 11 and 12, different strengths and limitations can be attributed to each approach. For example, the separate representative group adopted by the comparator epilepsy network (SS1), allowed for the inclusion of a greater range of representatives and so could be argued to be more 'representative' of the epilepsy patient community as a whole. However, a major limitation of this approach was that there was not sufficient professional capacity to act on all of the information generated. In contrast, in the intervention study (CS1), where there was also a separate representatives group, there was the professional capacity to act on the group's suggestions, but the presence of the 'known' clinical researcher appeared to inhibit discussion and debate. Representatives in the UKERN valued being part of the 'professional' groups as it made them feel properly integrated. Furthermore, the recruitment process they undertook helped ensure they had the self-confidence to actively participate. This also meant that they might not be seen to be really 'representative' of the epilepsy patient community and occasionally they were involved in meetings that were, from their viewpoint, a 'waste of time'.

Table 11: Strengths and limitations by site (i)

Summary of site processes	Strengths (S) and Limitations (L)
UKERN (main site): Integrated, personal/proximal, generic, partnership	
<p>Formal application and selection process for representatives</p> <p>Training day for representatives</p> <p>Representatives integrated within the network groups</p> <p>Six representatives in total</p> <p>Two representatives per network topic group</p> <p>No previous connection between representatives and professionals</p>	<ul style="list-style-type: none"> S The application process ensured a clear understanding of the representatives' roles (ED) S Representatives meeting the recruitment criteria had the confidence and skills to contribute to the meetings (see Sections 3.3 & 5.4) S The formal approach to training was seen as a benefit by the representatives (see Section 5.3.5) S Professionals within the integrated group had the ability and capacity to act on suggestions made by representatives (ED) S Representatives felt like part of the network, as they were integrated into the topic groups with other stakeholders (ED) S Having two representatives per clinical study group provided peer support for the representatives and a dual PPI perspective for the professionals (ED) L The nature of the formal selection process meant that representatives could be seen as not be truly 'representative' of the epilepsy community (see Sections 4.5.6 & 5.5.1) L In some situations, where representatives were only passively present, they felt their presence had been a waste of time (see Sections 5.2.2 & 5.5.5)
Comparator epilepsy network (sibling site one): Separate, proximal, generic, partnership	
<p>No selection criteria for representatives</p> <p>A 'Representatives' group involving two professionals and eighteen representatives</p> <p>Half of the meeting time given to representatives' own research ideas</p> <p>Half of the meeting time given to feedback to professionals in the wider network</p> <p>Ownership of the group lay with the representatives not the professionals</p> <p>Potential for future clinical-patient relationships between individual professionals and the representatives</p>	<ul style="list-style-type: none"> S No selection criteria potentially allows for greater 'representativeness' of the epilepsy community (see Section 3.2) S Both professionals and representatives felt the clear outputs from the group provided evidence, that the PPI was 'meaningful' (see Section 3.2) S Consistency in group membership allowed for self-management of group dynamics and increased representatives' confidence to contribute their opinions (see Sections 3.2 & 5.4) S Good group facilitation made representatives feel meaningfully involved and increased their confidence to contribute their opinions (see Sections 5.4 & 5.6) L The lack of clear roles specified from the outset of the group raised concerns among professionals around blurring of roles and 'power' imbalances (see Sections 3.2 & 4.5.4) L The separate nature of the group, and having only two professionals present meant that there was limited capacity for professionals to act on representatives' suggestions (see Section 3.2) L Not having a formal selection process for representatives, combined with some of the problems sometimes associated with having epilepsy, meant that some of the representatives did not always act 'appropriately' for a meeting situation. This could make it difficult to complete the agenda and increase the likelihood of members being offended or upset (see Section 3.2) or feeling like they were wasting time.

Table 12: Strengths and limitations by site (ii)

Site summary	Strengths (S) and Limitations (L)
Intervention study (child site one): Separate, personal/proximal, targeted, advisory	
<p>Consultation group Eight representatives Two professionals, one of whom worked with the representatives in a clinical capacity Informal selection criteria for representatives Agenda set by professionals prior to the meeting</p>	<ul style="list-style-type: none"> S Having set aims for each meeting that were then met provided clear outputs from each meeting, offering evidence to both the representatives and professionals that PPI was ‘meaningful’ (ED) S Having the professionals integral to the project present meant that they could explain why or why not representatives’ comments were being incorporated, providing evidence that they were ‘being listened to’ (see Sections 3.4 & 5.6) S The consistency of membership of representatives group allowed for self-management of group dynamics and increased individual members confidence to give opinions (see Section 5.4) S Representatives group established at the design/ funding bid stage so could potentially influence the whole research process (ED) L Only four representatives consistently attended meetings, this was not enough for those involved to feel they were being truly representative (see Sections 3.4 & 5.5.6) L The presence of the research lead, who was also acting in the capacity of clinician to some group members, inhibited discussions (see Sections 3.4, 4.5.4 & 5.6)
Clinical trial (child site two): Separate/integrated, personal, targeted, advisory	
<p>Feasibility survey involving representatives One representative on steering and data management group Feedback on participant information</p>	<ul style="list-style-type: none"> S The decision over whether or not to submit the research bid rested on representatives’ feedback, which was collected through the feasibility study. Offering clear evidence that the representatives’ input was being taken into consideration and, in turn, of meaningfulness of PPI (see Section 3.5) S PPI was seen as intrinsic to the research not an add on; it was valued by the professionals as part of the research process (see Section 3.5) L As PPI was seen as intrinsic to the research process, there was no formal plan on how it would be achieved and it appeared to happen on add-hoc basis. As such opportunities may have been missed when PPI could have improved the research process, e.g. during the design stage (ED) L Only one representative was a member of the steering group and the data monitoring committee. When she could not attend, there was no PPI representation. (see Section 3.5) Also it is extrapolated that this may lead to a lack of peer support.

6.4 Seven factors to ensure 'quality' PPI

Comparing my four research sites inevitably raised the question: is there one PPI approach that is better than others? Having considered the data in this comparative fashion, taking into account the four dimensions of my typology and drawing on the rest of my data analysis, I propose that it is not the 'approach' to PPI, in of itself, that determines 'quality' PPI but rather the alignment of aims, approach and purpose that facilitates 'better' PPI.

As discussed in my literature review, since PPI requires working with a diversity of perspectives in varying contexts for differing purposes, I support Ross et al's (2005) assertion that there cannot be a 'one size fits all approach'. For PPI to be effective, the approach used needs to align with its aims and purpose; and depending on the scale of the research project, multiple methods could be implemented, for example having a separate representative group and a representative on the steering group. However, building on the findings already considered in this chapter, I have identified seven factors that appear to cut across all of the approaches to PPI, within my research sites and that help to ensure 'quality' PPI:

1. *There should be a clear channel of communication between representatives and professionals, allowing representatives to see the effects of their contribution and ensuring the information reaches those with a capacity to act on it.* Participants within the UKERN (integrated) and the intervention study (CS1, separated) both emphasised the importance of the representatives' input being directly communicated to the professionals who have the ability to act on it, both to ensure that it is 'taken into consideration' and so that there is evidence that they are 'being actively listened to'.
2. *Professionals need to have good interpersonal and facilitation skills to help ensure representatives have both the confidence and opportunity to contribute.* This is particularly true of the 'facilitator(s)' (see Section 5.6) but holds true to all of the professionals involved.
3. *There needs to be clear roles and responsibilities for both professionals and representatives.* Having clear roles increases representatives' confidence (see Section 5.4), facilitates the provision of 'valid opportunities' (see Section 3.6) and reduces professional-representative boundary issues (see Section 4.5.4) (For more detail on the importance of clear roles see Section 6.5)
4. *Where possible, professionals should not have a direct clinical relationship with representatives, in order to limit role confusion and power discrepancies.* The

professionals in my sites who had clinical relationships with the representatives (Jess, SS1; Tom, SS1 and Nick CS1) noted the most difficulty with professional boundaries and in Nick's case his dual relationship with the representatives inhibited discussion.

5. *Training and support for both professionals and representatives is an important requirement.* Representatives viewed formal training as a benefit of taking part in the research process (see Section 5.3) and as helping to reassure them in relation to queries about how they could fulfil their roles. Additionally training and support in implementing PPI can help reassure professionals that they are 'getting it right' and help them to make informed decisions about which approach to PPI will most likely address their motivations and aims.
6. *It is important to allow for the development of rapport and self-confidence and the management of individual personalities. One way to achieve this is for group to meet on multiple occasions, with some consistency in group membership.* The importance of group 'self-management' of personalities was mainly been raised in the context of the comparator epilepsy network (SS1) and the intervention study (SS1) in relation to a variety of 'types' of representatives and learning to work with different 'difficult' personality types. The broader importance of 'getting to know each other' also held true in the UKERN, as both professionals and representatives found that 'getting to know' each other made them feel more confident about working together.
7. *Professionals need to be aware of, and make adjustments for, representatives' illness-related difficulties,* e.g. in the case of epilepsy, having awareness that tiredness can induce seizures and exacerbate memory problems and planning the timing of meetings according.

Using these seven 'quality' indicators as a framework by which compare and contrast the four PPI approaches used in my epilepsy specific sites at a more conceptual level allowed me to examine whether or not any one of my sites had a 'better' approach to PPI than the others, irrespective of their varying aims, approach and purpose.

In Table 13 I summarise how each of the sites was positioned in relation to each of the seven 'quality' factors.

Table 13: Positionality of epilepsy sites in relation to 'quality' indicators of PPI

Main site, UKERN Integrated, personal/proximal, generic, partnership	SS1, Comparator Epilepsy Network Separate, personal/proximal, generic, partnership	CS1, Intervention Study Separate, personal/proximal, targeted, advisory.	CS2, Clinical Trial Separate/integrated, personal, targeted, advisory.
1. channel of communication between representatives and professionals			
Representative sat on the same group(s) as the professionals and therefore directly communicated with them.	A lack of direct communication between the representatives' group and the rest of the network reduced the amount of PPI information the network as a whole had access to and the number of professionals with the capacity to implement the information.	Although the group met separately from the wider research team, unlike the comparator network there was direct communication with those whose responsibility it was to act on the information as the lead researcher attended the meetings.	The representative sat on the same group as the professionals The feasibility study (questionnaire) findings were turned into a report and distributed to the research team.
2. Professionals need to have good interpersonal and facilitation skills			
The three group leads all had good facilitation and interpersonal skills.	The representatives felt that the good facilitation of the group gave them each space to talk (which could be challenging given some of the 'difficult' personalities present) and the confidence to do so.	Both professionals had good interpersonal and facilitation skills.	While the data monitoring committee seemed to function well, managing the different professional stakeholders, I did not see them interact with the representative so I have no data for this indicator.
3. There needs to be clear roles and responsibilities for both professionals and representatives			
The formal application process meant that there was a written role description for the representatives so overall their role was clear. During some of the meetings representatives felt that there was no clear purpose in them being present.	The group was supposed to be representative-led making the professionals uncertain of their roles. Initially there was no clear role for the group but by the time of data collection they had established their own purpose.	Very clear roles, responsibilities and purpose overall and in each meeting.	Professionals had clear perceptions of what role the PPI representatives would fulfil in specific situations but had no overarching understanding of their role within the research I did not have the opportunity to interact with the representative so I have no indication if they were clear on their role.

Main site, UKERN Integrated, personal/proximal, generic, partnership	SS1, Comparator Epilepsy Network Separate, personal/proximal, generic, partnership	CS1, Intervention Study Separate, personal/proximal, targeted, advisory.	CS2, Clinical Trial Separate/integrated, personal, targeted, advisory.
4. Professionals should not have a direct clinical relationship with representatives			
None of the professionals had clinical relationships with the representatives and were unlikely to develop them in the future.	Professionals had the potential to be in a future clinical relationship with their representatives and had difficulties determining the extent to which they needed to maintain standard professional boundaries (see Section 4.5.4).	The lead researcher had a clinical or potential clinical relationship with the representatives and when he was present discussion was more stilted. He deliberately only took part in half of the meetings. The second researcher was not in a clinical relationship with the representatives.	No clinical relationship between the professionals and the representative on the data monitoring and steering group
5. Training and support for both professionals and representatives is an important requirement			
A training day was run for the representatives. The facilitators were given packs on how to facilitate PPI. Representatives were assigned mentors for support but did not hear from them	The professionals provided a lot of support for the representatives both within and outside of the meetings. While representatives did not have a formal training day like the UKERN they had to opportunity to attended generic PPI training events and members of the wider network gave more focused 'training' about their area of research. Professionals did not undertake specific training on how to facilitate PPI, rather they drew on their clinical training and interpersonal skills.	The facilitator undertook PPI training and found a mentor for support. Unclear what if any training was provided for representatives	I do not know what/ if training the representative was given Only one representative will be present at each meeting, so there will be potentially a lack of peer support The professionals interviewed in relation to the site had not undertaken any PPI training

Main site, UKERN Integrated, personal/proximal, generic, partnership	SS1, Comparator Epilepsy Network Separate, personal/proximal, generic, partnership	CS1, Intervention Study Separate, personal/proximal, targeted, advisory.	CS2, Clinical Trial Separate/integrated, personal, targeted, advisory.
6. Development of rapport and self-confidence confidence and the management of individual personalities			
<p>As part of the training day there was a ‘thank you dinner’. This allowed for the development of rapport both between the representatives and the professionals running the day.</p> <p>The group met on multiple occasions allowing for members to get to know each other.</p> <p>Many of the meetings were by tele-conference which may have inhibited relationship development as there was no social interaction either side of the meeting, and they tended to have very focused content.</p>	<p>The consistency in group membership, multiple meetings and good facilitation of the group increased representatives’ confidence to contribute and allowed for the self-management of different personalities and medical conditions.</p>	<p>Multiple meetings, and evidence of their involvement impacting on the research, allowed for the development of rapport, self-confidence and self-management</p>	<p>No data</p>
7. Professionals need to be aware of, and make adjustments for, representatives’ illness-related difficulties			
<p>As the patient representatives in the group largely appeared well, I think it was easier for the professionals to forget that adjustments needed to be made in comparison to the intervention study (CS1) and the comparator epilepsy network (SS1).</p> <p>When representatives were expected to travel to attend meetings they often compensated for potential difficulties themselves (see Section 5.5.1) rather than the network adjusting the travel and accommodation policies</p>	<p>The venue of the meeting was chosen to be easily assessable by public transport as many of the representatives could not drive.</p> <p>Professionals prompted representatives prior to the meeting or when work was pending to help compensate for memory problems.</p> <p>The group set guidelines for expected responses times for the network in order to give representatives enough time to process and respond to requests.</p>	<p>Allowances given for the illness-related difficulties that some representatives experienced in group/ social situations.</p> <p>Awareness that representatives might find some of the issues being discussed emotionally distressing impacted on the representatives selected.</p>	<p>No data</p>

As noted in the summary of the Clinical Trial (CS2) in Table 13 the fact that a representative had not yet been present during the meetings at the cessation of data collection meant that it was not possible to determine how the site was positioned with regard to all seven quality indicators. Focusing on the other three sites reinforces the findings in Section 6.3 that different strengths and limitations can be attributed to each approach. Based on this comparison, it could be argued that the UKERN had a *slightly* higher 'quality' approach to PPI in comparison to the other sites as it addressed more of the issues around establishing clear roles, training (of both professionals and representatives), facilitation and communication from the outset.

While my typology of PPI allows for a reconceptualization of different 'approaches to PPI' and the seven 'quality' factors cut across all of these approaches enabling their effective implementation, they do not in of themselves answer the central question 'what is meaningful PPI'.

6.5 What is meaningful PPI?

Throughout my data analysis it became apparent that rather than defining PPI by the different types, methods or approaches both the professionals and the representatives focused on the distinction between *meaningful* and *tokenistic* PPI, using these terms in antithesis to each other. Being responsible for tokenistic PPI was seen as morally reprehensible by the professionals. Tokenistic PPI from the professionals' point of view was seen as doing the '*bare minimum*', for example having a representative present so that it could be said that PPI 'had happened', even though the professionals concerned had either not wanted, been able to or allowed representatives the capacity to contribute in a 'meaningful' way. Factors that professionals associated with tokenistic PPI included: not providing representatives with sufficient information about the research, using too much jargon, not giving representatives the opportunity to voice their opinions and not taking representatives' contributions into account during the decision making process (see Section 4.5.2).

The representatives also felt that having the opportunity to give their opinion and it being listened to were both imperative for meaningful involvement. Evidence of being 'listened to' included seeing, or being told about, changes to the research linked to their contributions. The representatives built on this, expressing the view that meaningful

involvement occurred when they *could* potentially have an impact on what they were involved in; to an extent whether or not they actually *did* have an impact was secondary. For example, if they had given a suggestion and the professionals explained why they were not incorporating it, they still felt listened to (and therefore involved in a meaningful way) even though they had not actually had a direct impact. Understanding what they were being asked to comment on was seen as particularly important by the representatives. This did not necessarily mean understanding all details of the research or its medical components. Rather it meant having enough information to place the research in context and enough direction to know where to put their attention and focus (see Section 5.2.2).

Figure 16: Definitions of meaningful and tokenistic involvement

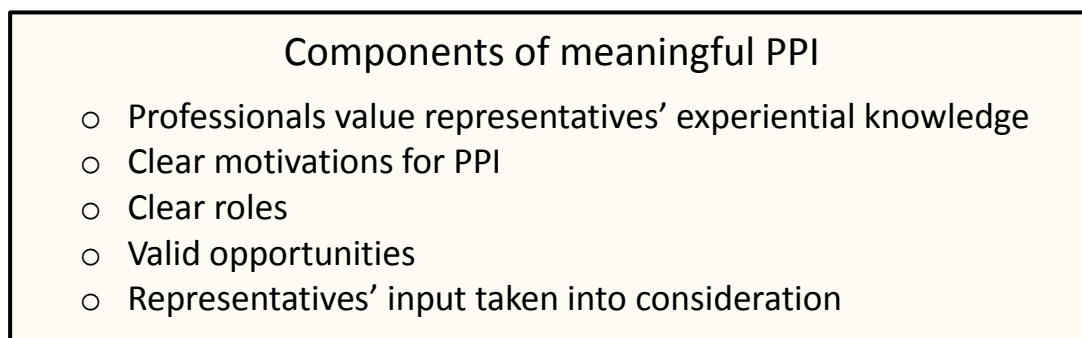
Definitions of involvement	
Meaningful involvement:	Representatives are involved in an <i>active</i> manner and are in a position to potentially impact on the research process.
Tokenistic involvement:	Representative(s) are only <i>passively</i> present in the research process, and not able to contribute to it in a way that has potential for impact.

Both the professionals and the representatives appeared to have developed their understanding of meaningful PPI by having observed or experienced what they considered to be tokenistic PPI, giving the impression of a perceived high prevalence rate of tokenistic PPI. Both groups viewed tokenistic PPI as a 'waste of time' and expressed the preference for a lesser amount of meaningful involvement, rather than involvement at all stages of the research process 'for the sake of it'. This position does not fit with the Department of Health's policy stance *to have PPI in all stages of the research process* (2006). Also the focus on meaningful versus tokenistic PPI may not fit easily within current models of involvement. For example, Boote, Telford and Cooper's (2002) 'levels of consumer involvement' identifies three categories of involvement: *Consultation* (researchers obtain feedback from representatives, representatives have no power to ensure their suggestions are acted upon), *Collaboration* (on-going partnership between professionals and representatives, representatives have some power in the decision making process) and

Consumer control (representatives hold all the power). This model, like several others (see Section 1.4.1), implies that power over outcome is equivalent to level of involvement. As such the more power the representatives have the more involved they are seen to be. The PPI literature is starting to acknowledge that this hierarchical criterion of power to denote the quality of involvement is an over-simplification (O'Donnell & Entwistle, 2004; Tritter & McCallum, 2006) Gibson et al 2012). Certainly, neither the representatives nor the professionals within my sites defined meaningful PPI in terms of power over outcome, but rather in terms of input and impact, (impact on research process in first instance but also on representatives and professionals). I maintain that PPI can be 'meaningful' for both the professionals and representatives even when the representatives have no 'direct power over the outcome'.

Based on this emphasis on 'meaningfulness' and the findings of my analysis I revisited the question: what is involvement? (see Section 1.4) and further interrogated the question, what is meaningful involvement (see Figure 16)? I submit that within the data presented in the previous chapters there are five components of meaningful PPI (see Figure 17). I am not proposing that all five must be present for PPI to be meaningful, but rather that the likelihood of PPI being meaningful is increased proportionally the more of these components are present. I will now give a brief summary of each of these components.

Figure 17: Components of 'meaningful' PPI



Professionals value representatives' experiential knowledge:

The professionals involved believe that representatives have, or potentially have, useful information to contribute. Without this underlying assumption professionals will be unlikely to meaningfully engage with representatives. As detailed in section 4.5.3 professionals find the time for activities that they value, as the perceived benefits (see Section 4.4) outweigh the perceived challenges (see Section 4.5). The professionals in all my sites, to a greater or lesser extent, clearly believed that representatives added valuable information to the research process. This belief seemed to an extent to be self-fulfilling. Because they valued the representatives' knowledge, they supported the representatives' active involvement and utilised the representatives' input, providing evidence to reinforce the belief that PPI is useful.

Clear motivations for PPI:

Both representatives and professionals (but particularly the professionals) need to have clear motivations for PPI in a given context, in order to help identify and facilitate opportunities for the representatives to fulfil their purpose. Having clear motivations for involvement such as the wish to ensure recruitment (CS2, clinical trial) or refine research design (CS1, Intervention Study) provides tangible ways by which to judge if PPI is having an impact on the research process. It also provides a framework for the type of PPI approach that needs to be implemented in order to achieve meaningful involvement.

Clear roles:

Establishing clearly defined roles and responsibilities helps to prevent conflict and boundary issues. It also allows people to know what is expected of them and increases confidence that they are focusing on the correct area. The importance of this is raised in the literature around functioning of multidisciplinary teams. The importance of clear roles was first brought to my attention by Emma and Lucy, the epilepsy charity advisers to the UKERN, who advocated the use of a role descriptor in the formal recruitment process, to ensure that all members of the network were clear on the representatives' role. This was reinforced by the boundary issues identified within the comparator epilepsy network (SS1). The professionals were unclear of the nature of their relationship to the representatives, resulting in tensions around codes of conduct (see Sections 3.2 & 4.5.4).

Valid opportunities:

Representatives are not just passively present but have an opportunity to actively contribute and are provided with appropriate information and support to do so. As detailed in Section 3.6 and discussed earlier in this chapter, each of the sites had different perceptions of what constituted a 'valid opportunity' and in turn endeavoured to provide them within their PPI process. What is salient here is that if representatives do not have the chance or support to 'voice' their opinions, the professionals will not have the ability to 'hear' them.

Representatives' input taken into consideration:

During the decision making process the contributions of the representatives need to be actively taken into account by the professionals. If they are not, then even with the other four components the involvement of representatives is likely to be tokenistic. This was an underling assumption present across all of my sites 'what's the point of having them there [representatives] if we don't listen to them?' This was supported by the responsibility that professionals felt towards the representatives, that having asked them to take part it would be disrespectful not to actively take into account their contribution (see Section 4.5.6).

6.6 Summary

Having considered the information from the preceding chapters I found that it was not appropriate or desirable to try to classify the type of PPI being implemented within my sites using the traditional PPI models (see Section 1.4.1). I therefore developed my own typology to describe PPI and then compared and contrasted these approaches to see if one of the approaches to PPI within my sites appeared to be higher 'quality' than the others. I concluded that it is not the approach to PPI, *per se*, that matters, but rather the alignment of aims, approach and purpose. I identified seven key factors that help to ensure 'quality' involvement regardless of the approach used. I then drew on my data to answer the question 'what is meaningful PPI?'; defining meaningfulness and identifying five components that, when present, help to ensure that PPI is meaningful and not tokenistic.

Although my typology of PPI, seven key 'quality' factors and the components of meaningfulness have been presented separately, they are all heavily interlinked with each other. Similar to Gibson et al's (2012) model of involvement (see Section 4.1.1) the combination of the 'typology of PPI', 'seven key factors' and 'the components of meaningful

PPI', provide a framework for conceptualising and reflecting on the PPI process. I also see them as useful for planning and implementing quality, meaningful, PPI. By systematically working through the four dimensions of the typology in relation to the purpose of their PPI, researchers would be able to identify the approach that would best achieve these aims. Once the overall approach had been determined the researchers could review if the seven key factors are automatically part of their approach to PPI or if they have to be actively incorporated, enabling effective or 'quality' implementation. For example if utilising 'separate' involvement, is there a clear channel of communication? If adopting a one of 'advisory' approach to PPI, how will rapport be built? In addition, considering the 'components of meaningful PPI' in relation to the chosen approach will help to avoid tokenism. In the discussion chapter I provide more detailed suggestions on the implementation of PPI in practice and draw out other main findings.

Chapter 7. Discussion

7.1 Introduction

In the preceding chapter I considered the information from Chapters four to six in order to compare and contrast different approaches to PPI in an epilepsy context and conceptualise 'meaningful' PPI. Building on this, in this chapter I draw together the main findings and place them in the context of the current literature, identify what they contribute to the current understanding of PPI and consider the potential implications of these findings for how PPI is implemented in policy and practice. Following this, I reflect on the research process as a whole, discussing the strengths and limitations of the chosen methodology and identifying ways in which my findings could be enhanced with further research.

7.2 Main findings in the context of the current PPI literature.

In the first part of my literature review (see Section 1.2) I explored the historical and political context of PPI, describing its evolution in health research in light of a combination of political and moral drivers. In the second part (see Section 1.6) I concluded that there is a lack of empirical evidence about the impacts of PPI. Linked to the historical context of PPI, the majority of the literature is theoretical or based on anecdotal evidence. This is a conclusion shared by a range of PPI review articles (Boote, Telford, & Cooper, 2002; Minogue et al., 2005; O'Donnell & Entwistle, 2004; Oliver et al., 2008; Staley, 2009a). I also determined that there is a prevailing focus on the potential benefits of PPI on both the research process and those involved, with little consideration of the possible challenges and drawbacks of PPI.

My study generated an extensive amount of information about the implementation process of PPI in the context of health research. The key findings can be presented in seven categories: motivations for involvement; 'meaningful' PPI; Typology of PPI; benefits and challenges of PPI; the importance of confidence and the facilitator; differences across sites and approaches; and, issues of power and perception. I will address each of these categories in turn and consider how they inform the literature.

7.2.1 Motivations for involvement

The professionals differentiated between the purpose, motivation(s), and benefits of PPI. They regarded the purpose of PPI as its primary function, the reason why it is done. The motivation(s) for PPI included specific reasons for conducting PPI in a given situation; and the benefits of PPI were the 'additional' positives that PPI brought outside of the original motivations.

In comparison, the representatives appeared to view purpose, motivation(s), and benefits of PPI as largely one and the same. I attribute this difference in conceptualisation to the different ways the two groups developed their understandings of PPI, which reflected their roles within the research. The representatives developed their understanding of PPI primarily through experiencing it, whereas the professionals tended to have preconceived ideas based on the literature, interactions with other professionals and training, which were then tested through their own participation in the PPI process.

The professionals believed that the overarching (non-site specific) purpose of PPI was to ensure that research was 'relevant'. Relevant research equated to 'beneficial' research that would be useful to the public. This emphasis on relevance may explain why it is one of the most commonly reported perceived benefits of PPI in the literature (Caron-Flinterman, Broerse, & Bunders, 2007; Elberse, Caron-Flinterman, & Broerse, 2011; Fisher, 2002; O'Donnell & Entwistle, 2004; Popay & Williams, 1996; Rhodes et al., 2002; Wright, Corner, Hopkinson, & Foster, 2007). For professionals in my study however, relevance appeared to be not just one of many potential benefits; rather it was the primary function of PPI. In addition to helping directly to ensure the research question was relevant, the professionals believed PPI helped improve research design and implementation, so indirectly increasing its relevance. The professionals also gave site specific motivations for PPI including: increasing the chance of obtaining funding (CS1), because it is ethically right to be inclusive (SS1) and to ensure adequate recruitment (CS2). Even taking the site specific motivators into account, the primary sustaining motivator seemed to be the professionals' underlying belief that the purpose of PPI was to improve the research process, thus making it more 'relevant' (see Sections 5.2.1 & 5.3). It seems important to note that the professionals did not appear to have any personal motivations for PPI outside of the research process. Overall the majority of professionals seemed to be of the opinion that PPI is essentially a

good thing and should happen, although they were 'sceptical' about how much impact PPI actually had.

Instead of focusing on increasing the relevance of the research, representatives articulated that the primary function of PPI was for professionals to get a '*different point of view*' or more specifically '*a patient's perspective*'. This different point of view was seen by the representatives as resulting from their experiential knowledge about epilepsy but also, in some cases, from the perspective of a non-professionally trained person. Representatives also believed that both of these factors allowed them to identify issues that would not be in the professionals' purview, for example, how patients may feel about the information being given to them or identifying difficulties in understanding the technical language used. While this overlaps heavily with the professionals' stance, the representatives focused more on how their knowledge could help improve individual components of the research process and improve the professionals' understanding of the condition, rather than its overall applicability or relevance.

The representatives also had more personal motivations for involvement. These included: having an innate interest in epilepsy and epilepsy research; the wish to feel like they were making a difference; helping others with epilepsy, valuing the research being undertaken and validating their knowledge and experience (see Section 5.3). These findings coincide with Canvin and Jacoby's (2006) research into the decisions of people with epilepsy about recruitment to clinical trials. They found that although patients expressed some altruistic motivations for involvement in research, they were largely driven by reasons related to 'self-interest'. Representatives' motivations for taking up a PPI role does not appear to be touched upon in the existing PPI literature.

Overall, both the professionals and the representatives appeared to be aware of the moral and political motivations of PPI, but were primarily motivated by pragmatic or consequentialist reasons. This suggests, as noted by O'Donnell and Entwistle (2004), that there is a need for more empirical evidence about potential impacts of PPI on the research process to motivate researchers who are more resistant to implementing PPI.

7.2.2 Typology of PPI

Having explored the PPI processes implemented in each site I concluded that it was not appropriate or desirable to try to classify the type of PPI being implemented within my sites using the traditional PPI models. I therefore developed my own typology to describe PPI. Within this typology I identify four key dimensions: i) Personal-Proximal-Distal, ii) Partnership-Advisory, iii) Integrated-Separated, iv) Purposive–Generic. Each of these dimensions is detailed in Table 10 and are presented as a non-static continuum rather than a dichotomy; and over the course of the PPI process the position on any part of the continuum may change. It is hoped that when used in conjunction with the ‘seven key factors key factors’ (see Section 6.4) this typology would provide a tool for conceptualising, planning and implementing PPI, ensuring the alignment of aims, approach and purpose and facilitating ‘quality’, ‘meaningful’ PPI.

7.2.3 Benefits and challenges of PPI

As previously discussed, both the professionals and the representatives believed that the main benefit of PPI was that it improved the research process (and in turn the relevance of the research). More specifically, the representatives thought that by ‘tweaking’ the research process, PPI could improve recruitment and dissemination. The professionals developed this point further by stating that PPI could help in the process of acquiring funding and ethical approval, and increase retention as well as recruitment of research participants. Based on my review of the literature, the potential for PPI to increase the likelihood of obtaining funding and improve retention appears to be absent from the literature. The other perceived benefits that were identified around removing jargon, increasing recruitment, expediting ethical approval and broadening of dissemination are congruent with the findings of other research (Boote, Baird, & Beecroft, 2010; Hanley et al., 2001; Iliffe, McGrath, & Mitchell, 2011; INVOLVE, 2012d; McDonald et al., 2006; Minogue et al., 2005; Staley, 2009a; Watson & Torgerson, 2006; Wyatt et al., 2008; Wight, Corner, J, Hopkinson, & Foster, 2006). The literature also suggests that PPI can facilitate more representative sampling, expedite data collection and improve selection of outcome measures (Elliott, Watson, & Harries, 2002; Boote, Baird, & Beecroft, 2010; Faulkner & Thomas, 2002; Fisher, 2002; Rhodes et al., 2002; Coupland & Maher, 2005). The representatives in this study also believed that interacting with representatives as part of the PPI process might help improve the professionals’ knowledge of what it is like to have epilepsy and improve their communication skills and, in turn, their clinical practice. This is

not something that the professionals identified as a benefit themselves. Other than the occasional comment (for example, Rachel stating she found PPI reassuring in terms of the value of the research) the professionals focused very little of their attention on the personal benefits of PPI beyond the improvements that it might offer to their research.

In contrast, the representatives identified a range of personal benefits that overlapped heavily with their motivations for involvement. In addition to their original motivations (innate interest in epilepsy and epilepsy research; the wish to feel like they were making a difference; helping others with epilepsy; valuing the research being undertaken and validating their knowledge and experience) they also valued the opportunity to learn about epilepsy and epilepsy research in greater depth and the opportunities PPI gave them for interacting with other representatives and the professionals. A subset of the representatives also found increased self-confidence was a benefit of their PPI role. While these benefits to representatives are discussed briefly in the literature (Minogue et al., 2005; Newell & South, 2009; O'Donnell & Entwistle, 2004; Rhodes et al., 2002), the representatives in my study placed more emphasis on personal interest and the learning opportunities they associated with PPI (see Section 5.3), whereas the existing literature focuses on the positive changes in representatives' self-perception (Minogue et al., 2005; Newell & South, 2009) and interactions with peers (Minogue et al., 2005; Rhodes et al., 2002).

The representatives in my study also recognised a range of challenges that arose as part of their PPI role. These included practical issues such as information technology problems and managing conflicting obligations, problems of understanding scientific language and jargon and time commitments. Also worries about how representative they were of the epilepsy community as a whole, the potential emotional effects of being involved in research linked to a condition of which they had personal experience, and the need to work around their individual health issues. As I indicated in Section 1.6.2, other than the suggestion within the literature that some representatives found increased information on their condition elevated their anxiety levels (Rummery, 2009) and the concerns some representatives had about the perceived level of responsibility PPI brings (Newell & South, 2009), the PPI literature does not address these more challenging aspects of PPI for the representatives. Yet without an understanding of the potential challenges that representatives experience, professionals cannot take them into account when planning support and training needs.

The professionals also reported experiencing challenges around time commitments, organisational practicalities (such as additional complexities when organising meetings and liaising with different university departments to ensure representatives received payment) and worries about how representative of the epilepsy community their representatives were. They also expressed concerns about the best way of conducting PPI, worrying about upsetting or offending the representatives, the possible blurring of their academic roles and the erosion of patient-clinician boundaries. Coupland and Maher (2005) suggested that the 'blurring of roles' provides professionals with new opportunities for learning and developing systems, as well as being disconcerting for the individuals involved. This more positive slant on the 'blurring of roles' does not appear to have been experienced by the professionals in my research sites.

The professionals' and representatives' concerns about how to ensure that representatives are truly 'representative' of the group have also been raised by other authors (Entwistle, Sowden, & Watt, 1998; Entwistle et al., 1998; Rhodes et al., 2002). However, I would submit that it is not possible for one person or a small group of people to be truly 'representative' of a given population and suggest that trying to achieve true 'representativeness' is a fallacy that, in part, stems from the terminology used. Perhaps using terms such as 'stakeholder(s)', 'partner(s)' and 'diverse purposive sample of the public' would help overcome some of the complexities associated with the term 'representative(s)'. Nevertheless I will continue to use the term 'representative' in this thesis for constancy and clarity.

7.2.4 Meaningful PPI

Both representatives and professionals differentiated between 'meaningful' and 'tokenistic' PPI. As this has already been discussed in depth, in relation to the literature in other chapters (see Section 4.5.2, 5.5.2 & 6.5) only a brief summary is given here.

Tokenistic PPI was seen as doing the 'bare minimum', having representatives present but not 'allowing' them to contribute in an active way to the research and was regarded as the opposite of 'meaningful' PPI. The representatives stressed that meaningful involvement occurred when they *could* potentially have an impact on what they were involved in; to a certain extent whether or not they actually *did* have an impact appeared to be secondary.

Being responsible for tokenistic PPI was seen as morally unacceptable by the professionals and both groups viewed tokenistic PPI as a 'waste of time'. They expressed the preference for a small amount of meaningful involvement rather than involvement at all stages of the research process 'for the sake of it'.

Based on the findings of my analysis I believe that there are five components of meaningful PPI: (i) that professionals value representatives' experiential knowledge; (ii) that there are clear motivations for PPI; (iii) that professionals and representatives have clearly designated roles; (iv) that there are valid opportunities for representatives to contribute; (v) and that representatives' input is taken into consideration. With the exception of (v) I am not suggesting that all five must be present for PPI to be meaningful, but rather that the likelihood of PPI being meaningful is increased proportionally when more of these components are present.

7.2.5 The importance of confidence and the facilitator

In Section 7.2.3, when examining the perceived benefits of PPI, I discussed how some of the representatives found increased self-confidence was a benefit of their role. This is congruent with Newell and South's (2009) findings that representatives report increased confidence in their own capabilities and influence. However, there is nothing in the literature which addresses what gives the representatives confidence in their knowledge or what affects their confidence to express views in a given situation. As noted in Section 5.4 the importance of having confidence cannot be overstated. If representatives do not have the confidence to make their views known, then according to their own and the professionals' definitions are they are not and cannot be meaningfully involved. Building on this, three key areas of 'confidence' were identified; representatives' confidence in the value of their own knowledge; their confidence to speak in groups; and their confidence to disagree with the professionals. Factors that emerged as positively influencing representatives' confidence included: their own professional occupation, group dynamics, consistency in group membership, past PPI experience, level of rapport with professionals and other representatives, feeling that they were being listened to and the skill of the facilitator. Conversely, issues around understanding the language used (jargon) and perceiving their involvement as tokenistic appeared to negatively impact on confidence.

In relation to these factors, the influence of the group facilitator appeared to be paramount, as the facilitator set the tone for the group interactions, managed group

dynamics, created space for individuals to contribute and gave representatives evidence of their impact. Hewlett et al (2006) support this observation, by stressing that the chairing of a meeting is a key factor in enabling representatives to contribute. Therefore the choice of facilitator is important when making decisions about implementing PPI. Both the representatives and professionals noted that having a clinical-patient relationship with the group facilitator complicated their interactions. Because of this I would recommend that, where possible, the primary facilitator is not also the representative's clinician.

7.2.6 Differences across sites and approaches

Research Objective 4: *'To compare different approaches of implementing PPI, by contrasting the experiences of the professionals and representatives across the different research sites'*, was addressed throughout the result chapters. Specific focus was given to this objective in Chapter 6 (see Section 6.3), when the benefits and limitations of each approach were detailed and explored (see Tables 11 & 12). I suggested that it is not possible to advocate one of these approaches over the others but identified seven factors that appear to cut across all the approaches to PPI within my sites and that helped to ensure 'quality' PPI (see Section 6.4 & Table 13). In particular I propose that it is the alignment of approach, purpose and 'meaningfulness' that results in high quality PPI.

7.2.7 Power of perceptions.

During the discussion section of Chapter 3 (see Section 3.6) I described how the professionals' preconceptions about involvement impacted on their decision making process. On further reflection it was clear that the professionals held a number of preconceptions or beliefs about PPI, all of which could influence the PPI experience. These included: when representatives could have an impact; the representatives' capabilities; the problem of *those* representatives; how important it was for representatives to be 'representative' of the sample population and whether PPI was worth the time and effort involved. In turn the representatives also had beliefs about the professionals, the most pertinent of which was that they thought professionals would prefer to hear the opinions of fellow colleagues over those of the representatives. This appeared to strongly influence when and how the representatives contributed to the research process. Corroborating the work of Thompson et al (2012), it appears that representatives valued professional or 'certified' forms of expertise over their own, and believed that the professionals did as well. This seemed to be in direct conflict with the professionals' expressed view that they would

prefer to hear from the representatives in project team meetings, because they had other opportunities to access the views of their fellow professionals.

This deferral to the 'expert position' by the representatives resonates with Pilnick and Digwall's (2011) critical review of the asymmetry that is present in the context of doctor-patient interactions in clinical care. They argue that asymmetry in the power dynamics of patient-clinician relationships is inescapable, due to patients' reliance on the clinicians' knowledge and the perception that they (the clinicians) have the responsibility for determining what action is to be taken. This results in a 'functional asymmetry' which both parties reinforce. In the context of PPI, this functional asymmetry seems to be reinforced where, in addition to the professionals feeling responsible for the representatives wellbeing, the decision making power and research knowledge lies with them. Like Pilnick and Digwall I would argue that these cultural and functional power discrepancies are difficult to remove. However, their effect can be minimised by those involved in the process being aware of them and providing good facilitation.

7.3 Recommendations

This section explores the potential implications of the thesis findings for the implementation of PPI in practice and policy.

7.3.1 Practical recommendations for implementing PPI

When discussing 'meaningful' PPI and the question: *does the approach matter?* (see Sections 6.2 & 6.3.1 respectively), I identified some suggestions for the implementation of PPI. Incorporating these with the rest of my data I have identified 13 practical recommendations for optimising the implementation of PPI:

1. Having clear motivations for PPI before initiating PPI. This will help to identify and facilitate opportunities for representatives to fulfil their purpose.
2. Providing clearly defined roles and responsibilities: thus helping to prevent conflict and boundary issues. This will also allow people to know what is expected of them and increase confidence that they are focusing on the correct area.
3. Undertaking PPI early in the research process, preferably before the funding application is submitted, to ensure maximum 'relevance' as arguably this is the time when representatives can have the most impact on the research process.

4. Implementing PPI at time points and stages when representatives can have a real impact on the research process, rather than at every stage 'for the sake of it' to prevent it being 'a waste of time'.
5. Creating valid opportunities for involvement: representatives should have an opportunity to actively contribute and be provided with appropriate information and support to do so.
6. Ensuring consistency in group membership, of both professionals and representatives, to aid establishment of rapport and to allow people to learn how to work with conflicting personalities and increase the representatives' confidence to contribute.
7. In line with the above point, the group should meet on multiple occasions to allow for the development of rapport, confidence and self-management of personalities.
8. If there is an extended period of time between meetings, representatives would benefit from contact with the professionals, updates help them feel involved and valued.
9. Identifying a facilitator who:
 - i. Ideally is not the representatives' clinician, as this exacerbates issues of power and blurs professional boundaries.
 - ii. Should be linked to the research project to allow for direct feedback.
 - iii. Should have good interpersonal and facilitation skills to help ensure representatives have the confidence and opportunity to contribute.
10. Provide training to professionals regarding: the background, methods, possible impacts and how to ensure high quality PPI.
11. Provide training for representatives as appropriate so that they understand the context of the research they are being asked to comment on.
12. Ensuring clear channels of communication between representatives and professionals, ensuring there is feedback allowing representatives to see their impacts. This also makes sure information is with those with a capacity to act on it.
13. Ensuring professionals are aware of, and make adjustments for, representatives' illness-related issues; e.g. in the case of epilepsy, having awareness that tiredness can induce seizures and exacerbate memory problems, therefore meeting should take place at appropriate scheduled times.

7.3.2 Policy recommendations

In Section 1.5.3 I explained that current policy documents advocate that: “... *patients and the public must be involved in all stages of the research process*” (DH, 2006, p.34). Based on the discussions around what constitutes tokenistic PPI and the identified practical challenges of PPI, I would suggest that emphasis should be placed on implementing strategic, meaningful PPI rather than advocating PPI be implemented routinely in all stages. I would also suggest that funders need to ask applicants to be explicit, not only about *how* they are going to implement PPI but also about *why* they are going to implement PPI, in order to ensure that there is a clear rationale for involvement outside of the need to do so to obtain funding. Funders should not be prescriptive as to how PPI is implemented but rather should seek to ensure that the approach proposed matches the purpose. In addition, if funders value PPI they need to provide adequate funding to support it at the earliest stage of development and throughout the research process.

My work suggests that Universities need to support researchers with training and resources; providing money in order to allow PPI in the grant development stage; having clear procedures for the payment of representatives; and allowing researchers the time and providing them with resource to implement PPI. Finally, policy makers should request feedback on the positive and negative impacts of PPI in order to extend the current PPI evidence base, about the potential benefits and costs of PPI.

7.4 Strengths and limitations

Within any research project it is inevitable that there are constraining factors. As a single researcher, approaching the complex area of PPI during a restricted time period, my work is no exception. In this section I offer some reflections on the research process as I experienced it and my ideas for further research. In Section 2.4.2, I described how to assess the quality of ethnographic research, indicating that Hammersley (1990) offers a composite list of evaluation criteria that are specific to ethnographic research, four of which are considered key validity measures for an ethnography (Savage, 2000, p.1401):

1. The extent to which the influence of the research design and strategy on findings is considered (the reflexivity of the account).
2. The extent to which findings have relevance to those in similar settings.
3. The credibility of the account to readers and those studied.
4. The consistency of claims compared with empirical observations and data.

I will be using these four validity measures as the framework for this section

7.4.1 The influence of the research design and strategy on findings

As noted in Chapter 2, instead of planning precisely what will be done at each stage, an ethnographic methodology responds to the research findings as they unfold and narrows its focus through on-going analysis (Lofland, 2002). In tune with the developing nature of the method, sites may not be predetermined but rather chosen as the research develops, as insights are gained, and to some extent by chance (Hannerz, 2003). This method of site selection can be a problematic aspect of multi-sited ethnography, as there is a chance that optimal data might not be obtained (Lofland, 2002). One of the aims of this research was to explore PPI across the entirety of the research process. It quickly became apparent that the research sites associated with the UKERN were all in the early stages of the research process and therefore it was not possible to explore the role of PPI in later stages, for example during data analysis and the dissemination of findings. Due to the slow nature of the process of obtaining research funding, one of the potential sites, a clinical drug trial linked to the UKERN, saw little activity during the data collection period and therefore was not included in my study. The limited time frame for data collection also prevented me from observing PPI in the management and data monitoring committees of CS2 (Clinical trial). Arguably however, it is at the early stages of the research process where PPI may have the most impact on the design and implementation of a project and my sites provided an excellent opportunity to look at different approaches to PPI at the design stage of multiple trials within the same disease context. As some of the professionals' motivations and perceptions of the benefits of PPI, such as increased recruitment and relevance, may be less salient in later stages of the research process, further research is needed to see if there are different associated motivations, benefits and challenges of PPI across the different stages of the research lifespan. I am also aware that the emphasis I have placed on the importance of PPI in the design stage might be overstated as a result of the sites.

When reflecting on the ethnographic nature of this research the advantage of multiple methods of data collection was clear. A defining characteristic of ethnography is participant observation, with the researcher participating in the daily lives and events being studied over an extended period of time (Hammersley & Atkinson, 2003), in order to access information that would not be revealed through interviews alone. I found this held true particularly when exploring the challenges associated with PPI. During my observations both the professionals and representatives would allude to or explicitly state things they found difficult, about the PPI process. They did not then articulate these problems within

the interviews, unless I directly questioned them. Therefore, I propose that I was able to establish a more balanced and holistic understanding of PPI than would have been achieved by interviews alone. In Section 2.6.1 I asserted that the observational and longitudinal nature of the ethnography helped me to establish rapport with the participants, allowing me access to more honest and inclusive accounts. I feel this was particularly evident in the UKERN when comparing the transcriptions of my interviews at time point one, with interviews with the same participants at time point three. The latter interviews were far more informal than earlier ones, with participants talking more as they might with a friend than an interviewer, making regular reference to the fact: '*you were there*'. Building on the information from the multiple data sources, this rapport added to the breadth and depth of information collected and in turn providing more nuanced findings.

7.4.2 Relevance of findings in similar settings

To explore the experience of PPI required that the professionals sampled all had PPI experience. As I only had a limited capacity regarding the number of professionals who could be interviewed, I focused on professionals responsible for facilitating PPI. The advantage of this was that these professionals were involved in every stage of the PPI process and as such had experiences and knowledge that other professionals did not (for example the other UKERN clinical study group members). Consequently the findings are based on a subset of professionals' perceptions and experiences and do not take into account the views of professionals who are more peripherally involved in PPI, or those who choose not to engage with PPI at all. Further research is needed to develop an understanding of the perceptions of PPI from the position of those professionals who adopt a more passive, ambivalent or negative stance towards PPI.

The findings of this study are largely situated within epilepsy research. Some of the key findings from the epilepsy specific sites resonated heavily within my interviews with the PPI leads for the UK topic specific research networks (including: importance of a clear purpose, issues with *those* representatives, general scepticism from professionals and practical issues) suggesting a level of transferability to the findings. However, differences between my findings and the work of Thompson et al (2012) suggest that not all of the findings are applicable in other health research settings. Thompson et al (2012), found that cancer representatives draw on their relevant expertise (career, education or training) in addition to their experiential knowledge to 'legitimise' their position as a credible representatives.

This differs from the epilepsy representatives' perception that the more professional they are, the less 'legitimate' or 'representative' they are of the epilepsy community as a whole. In addition, Thompson et al found that cancer representatives did not feel it was their place to challenge the professionals but rather to support them; whereas, my representatives considered this a key component of their PPI role. In order to more clearly understand the transferability of my findings, further research is needed into the experiences of those involved in PPI in different research contexts.

7.4.3 The credibility of the account

In line with the ethos of this research, I considered it important that representatives' perspectives were considered at multiple stages in my own research process (see Section 2.10). In addition to my first consultation with the members of the Epilepsy Action Research Network (EARN), I had originally planned to go back to the EARN members who had given me permission to contact them a second time during my data analysis phase. Unfortunately due to time constraints, this has not yet happened. However, I feel the values of PPI have been maintained though the iterative ethnographic nature of the research, with information from each step informing the next, ensuring that all my participants influenced the research process. In addition, I perceive the credibility of the account to 'those studied' was ensured though the extensive respondent validation or 'member checking' described in section 2.4.1 that was an integral part of this research process.

While I maintain that I have systematically and extensively supported my findings with examples from my data, Hammersley's' (1990) fourth assessment criteria: *'The consistency of claims compared with empirical observations and data'* and the first part of the third criteria: *credibility of the account to readers*; must be determined by you, the reader.

In my methods section that I started this thesis with no: *"particular understanding of the best method(s) for implementing PPI, or the specific benefits and challenges. I started from a value position that people with epilepsy and their families should be involved in epilepsy research; and that, if done well, PPI can increase the quality of research and also have an impact on those involved"* (see Section 2.3).

While it is still true that I believe that PPI is important and largely beneficial, I have gained a more in-depth and nuanced understanding of the issues regarding its implementation and

the potential benefits and challenges. This is something I will take with me as I move forward in my research career.

7.5 Conclusions

In this thesis I endeavoured to generate a detailed understanding of patient and public involvement in health research, focusing on the experiences and perceptions of those involved. The multi-sited ethnographic approach allowed for an in-depth, direct comparison across a variety of approaches to PPI within the same condition, something that is currently lacking within the literature. It allowed for PPI to be explored at both a conceptual and practical level, looking at the benefits and challenges that representatives and professionals experience as part of their involvement in PPI. It also provided clear suggestions for the implementation of PPI in policy and practice.

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Appendices

- Appendix 1 Summary table of selected references
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- Appendix 3 Interview topic guides
- Appendix 4 Approach letter
- Appendix 5 Ethics approval
- Appendix 6 Participant Information and consent forms
- Appendix 7 Documents Re. PPI in this thesis

Appendix 1. Summary of selected references

After the original 229 references were collated I conducted a citation search for each using: PsycInfo, Web of Knowledge and Google Scholar. I included Google Scholar as it accounted for a lot of the grey literature that the other databases do not and is now accepted as a valid tool in literature reviews (Kuss & Griffiths, 2012). The numbers of citations reported across all three search engines were comparable with reference to journal articles. In order to be consistent, the citation number given below is the number of citations a reference had according to Google Scholar in January 2012. A citation number of N/A denotes a reference added after the original literature search. For ease of presentation, in this table any paper with more than two authors is identified by the first author then et al.

Table 14: Summary of selected references.

Author & Year	Citations	Focus of the paper	Methods	Main findings	Strengths and limitations
Abma (2005)	21	A responsive-constructivist approach to evaluating PPI	Case Example	That this approach to evaluation fits with the aims of PPI. Barriers to 'dialogue'	S: Highlights potential barriers, Uses a clear worked example L: The reflection process used is not clear, so it is not transparent how they reached their findings
Abelson et al (2003)	130	Deliberative framework applied to PPI in the health sector	Literature review	No direct comparisons of models of engagement, 4 key principles for design and evaluation of PPI	S: Deliberation as a framework for PPI L: Methodology of literature review is limited, missing information in inclusion/ exclusion criteria, does not list total number of articles selected
Allsop et al (2010)	5	Methods of involving children with disabilities	Literature review	Tailoring information, giving feedback and not using proxy information are key to involving children	S: Takes into consideration involvement methods from other disciplines L: Says it is a review of the literature but is actually a discussion paper. Doesn't recommend methods
Andejaski et al (2002)	14	Impact of PPI on prioritising research proposals	Content analysis & questionnaire	Voting patterns were similar for representatives & Professionals	S: Evidence based, comparative, evaluates impact L: Superficial as reasons for prioritisation not looked at

Author & Year	Citations	Focus of the paper	Methods	Main findings	Strengths and limitations
Avard et al (2010)	42	PPI models promoted in policy documents	Literature review	Mostly consultation and collaboration recommended in policy documents	S: 5 countries utilised. Extensive systematic review. L: Did not include all relevant documents.
Barber et al (2007)	19	Methods of PPI in NHS research	Survey	17% of research actively doing PPI. Steering group membership, designing interments and research design most common methods.	S: Sampling frame and generalizability L: Professional response bias
Bastian (1994)	34	PPI in the Cochrane Collaboration	Discussion paper	The need to account for culture clashes & expectations	S: Accessibility. L: Referencing inconsistent, the reader cannot tell what is opinion or fact.
Beresford (2002)	85	Looking at past PPI in research and suggesting ways forwarded.	Discussion paper	That 'future' research into PPI needs to be systematic and critical taking the different methods and philosophical stances into account. PPI needs greater priority on the social policy agenda	S: Looks at a range of models. L: No parameters defined in terms of what is being covered in the paper
Blair & Minkler (2009)	56	Participatory Action Research (PAR) with Older Adults	Literature review	The importance of valuing the experience of the 'elders' the need for bidirectional trust and effective training	S: Did not include study's where 'elders' were only subjects or part of focus groups ('real' involvement only) L: Limited focus on the challenging aspects of PAR
Boote et al (2010)	41	Peer reviewed case studies of PPI in design of health research	Literature review	4 key contributions to design, 5 main barriers, 4 facilitating strategies	S: Clear suggestions to facilitate PPI. Strict inclusion criteria L: Did not include 'prioritisation' stage, only included peer reviewed papers
Boote et al (2011)	0	PPI in research design	Literature review	7 papers Discuss PPI in research design, Barriers & facilitating strategies given	S: Inclusion criteria, applicability of finding L: No model comparison, number of reviewers missing

Author & Year	Citations	Focus of the paper	Methods	Main findings	Strengths and limitations
Boote et al (2012)	N/A	How PPI can lead to researchers ideas being abandoned	Reflective case Study	PPI can prevent irrelevant research projects from being pursued. The earlier PPI occurs the less researchers time is wasted	S: Focus on an example were PPI resulted in research being discontinued L: No information on the reflective process
Boote et al (2002)	81	Description of PPI in research	Critical review	4 key areas for further research	S: Explores all key aspects of PPI and associated arguments L: Little focus on the effect of PPI on the research process. Don't explain selection process for literature
Brett et al (2010)	N/A	Conceptualisation, measurement, impact and outcomes of PPI	Systematic Review	Nature of the PPI evidence base, importance of context and process, impact on people involved	S: Scope of the review, has clear recommendations L: Breadth means explanations of finding lack depth
Brisolara (1998)	48	PPI in evaluating social programmes	Discussion paper	"Critical questioning and reflexivity are integral to the PPI process". PPI makes a "powerful contribution to the development of practice and theory"	S: Highlights some of the contradicting information around the origins of PPI and incorporates a variety of theoretical stances L: Does not give any suggestions how current debates can be addressed in practice. Does not say exactly how they contribute to the evaluation process
Caron-Flinterman (2005)	28	To gain insights into how representatives prioritise research	Focus groups & questionnaire	The top priorities for research for Asthma suffers in the Netherlands	S: Used participant validation to check findings L: Do not ask why they rank that way which is key to the research question
Caron-Flinterman et al (2005)	31	Added value of PPI in Biomedical research	Interviews	3 types of involvement (demands, ideas & judgments) PPI has a positive influence on all stages of research	S: Interviewed the professionals and patients L: Detail of analysis missing, very focused analysis, no differentiation in perspectives
Caron-Flinterman et al (2007)	24	PPI in decision-making in biomedical research	Workshop & interviews	Current strategies not effectively involve patients	S: Findings based on mixed methods data collection L: Superficial data analysis

Author & Year	Citations	Focus of the paper	Methods	Main findings	Strengths and limitations
Chalmers (1995)	79	Clinician's/ researchers perspective on being a Patient involved in research	Discussion paper	Some benefits of PPI in research	S: It provides an interesting perspective on PPI L: It is based on one person's perceptions/ experiences does not add to the evidence base
Charles & DeMaio (1993)	95	A conceptual framework to categorise PPI	Discussion paper	A framework that incorporates Decision-making Domains, Role perspectives and level of participation	S: Clear argument for the need of a framework for evaluating PPI L: Limited justification for the three components of the framework. No evidence of its usability
Coupland & Maher (2005)	18	Evaluating representatives as researchers	Interviews & focus groups	Motivations for involvement, benefits, challenges, conflict resolution, blurring of roles	S: Looks at both perspectives, empirical evidence L: Interviews conducted by member of the team, more details of analysis needed
Crawford et al (2002)	289	Papers that describe changes to health services based on PPI	Systematic review	PPI has an impact on health services and the people involved in the process but limited evidence of impact	S: Reviewed over 300 papers including grey literature L: Lacks depth when describing impacts
Dickens & Picchioni (2011)	2	The terms used to refer to people who use mental health services	Literature review	Patient' is the most preferred term in the UK for mental health service users	S: Breadth of search terms used L: Did not include qualitative studies or professionals opinions
Dowling et al (2004)	160	Conceptualising successful partnerships	Literature review	5 key types of process related success and 5 key types of outcome success. Little hard evidence of improved outcomes	S: Links to wider partnership research L: Does not address impact on professionals
Edwards et al (2011)	N/A	Consulting parents in the design of a RCT	Description of PPI in a RCT	PPI improved research design and participation rates	S: Clear description of PPI method and specific examples of impacts L: More detail on why they responded to some suggestions over others would be useful

Author & Year	Citations	Focus of the paper	Methods	Main findings	Strengths and limitations
Elberse et al (2011)	4	To what extent representatives were included in decision making	Qualitative case study, interviews & observation	representatives felt lessened to, Researchers felt it when well but analysis suggests they were not fully included	S: Triangulation of data L: Information in data analysis is missing
Elliott et al (2002)	12	Using peer researchers to access hard to reach populations	Reflections from Authors	lots of support needed, researchers learnt about culture or participants, increased data collection	S: Clear integrated involvement L: Not clear how these conclusions were drawn/ anecdotal. No representatives feedback
Entwistle et al (1998)	92	A conceptual Framework to facilitate PPI	Discussion paper	The need for planning of PPI with a focus on outcomes and process	S: Provides a logical process for researchers to work though when making decisions regarding PPI. L: Does not justify the framework. Limited evidence for its suppositions
Faulkner & Thomas (2002)	11	The value of PPI in psychiatry research	Editorial	User research creates more ecological valid & clinical applicable outputs	S: Well written, range of issues covered. L: Opinion pieces but limited information of what these opinions are based on
Fisher (2002)	31	How PPI benefits technical aspects of social research	Discussion paper	PPI can bring technical enhancements to the research design process	S: Raises issues important to practitioners L: Unclear what evidence the conclusions are supported by
Florin & Dixon (2004)	39	Policy documents related to PPI in Health care	Short discussion paper	Current policies to increase PPI are piecemeal and disparate	S: Clear information, raising many salient points L: Due to the length of the article lacks depth
Fudge et al (2008)	36	How policy on User involvement is interpreted and implemented.	Qualitative Ethnography	Values, commitment and organisational structures are key in implantation of PPI. Benefits are hard to quantify	S: Followed over an extensive time frame, interviewed people that declined to be involved as well as those that were involved L: does not discuss the participants experiences/perspectives of the process or distinguish between groups. Not clear at what time point the interview took place or the link between the field and the ethnographer

Author & Year	Citations	Focus of the paper	Methods	Main findings	Strengths and limitations
Gillard et al (2010)		Is there a difference in the interviews and data analysis conducted by representatives and researchers? How is this measured?	Secondary data analysis	PPI does make a difference. Secondary thematic analysis of interview transcripts is a robust approach for evaluating impact of PPI on the research process	S: clear, replicable method of measure impact in this context L: Joint interviews initially may be a confounding variable. Small sample
Goodare & Lockwood (1999)	56	The role of PPI in research and related publications	Discussion paper	Medical journal should insist on PPI at all stages of clinical research and have PPI in the review process	S: Draws attention to the need to have PPI in dissemination. L: Lacks depth- due to length of editorial
Gustafsson & Driver (2005)	40	PPI policy and its implementation is Sure Start.	Discussion paper	Unclear	S: Looks in depth at the role of general government ethos' L: Confusing methodology unclear on sample and methods of data collection
Hanley et al (2001)	75	Audit Frequencies and types of PPI in RCT	Questionnaire survey	1/3 of centres reported PPI, 46 reported positives (inc. Improved patient information) of PPI only 9 noted negatives PPI	S: Large sample size L: Does not look at representatives perspective
Holmes et al (2002)	50	Description of setting up a cohort study in a hard to reach population using community researchers	Discussion paper	The establishment of a cohort for longitudinal study, increased use of health service	S: Demonstrates the value of community control in research, representative PPI representatives L: limited evaluation of the PPI
Iliffe et al (2011)		Benefits of PPI facilitated by a research networks	3 explanatory case Study's	Remedial action in helping studies that are not recruiting to target, problem solving in sensitive research topic areas, linking researchers to PPI sources	S: Evidence based, Shows Impact L: Only focused on benefits. No comparison of methods

Author & Year	Citations	Focus of the paper	Methods	Main findings	Strengths and limitations
Kellett et al (2004)	69	To demonstrate that with training and support children aged 8 - 12 can be effective researchers and empowered	Case studies	Evidence that 10 year olds can be effective researchers	S: The children/ PPI were included as Authors. Highlights the need for training and working round the representatives ability L: Evidence about empowerment is anecdotal
Krieger et al (2002)	62	Examples & lessons learnt from Seattle partners for healthy communities (SPHC)	Descriptive paper	Participatory research methods enhance research projects	S: Looks at a combination of take holders interactions not just researcher-public L: Anecdotal evidence, only the researchers perspective is reported
Lindenmeyer et al (2007)	12	Benefits of PPI to research and researchers	Interviews & discussion group	Balance of power, increased funding, improved research design, increased relevance & credibility	S: Evidence based, level of detail on the model L: Benefits only, focus of paper is constantly shifting
Minogue et al (2005)	13	Impact of PPI in research	Survey & audit	Benefits for representatives mainly personal, benefits for trust was having users perspectives and focus	S: look at both PPI & professional perspectives, focus on impact L: No detail on data collection & analysis
Mitton et al (2005)	29	Scoping lit review around PPI in priority setting	Literature review	On-going consultation most common. Cost biggest barrier	S: data source from a range of disciplines were included L: Level of detail
Morrow et al (2010)	44	A 'process' model and measure for 'quality' involvement	Discussion paper	The need to look at process not just outcome, The importance of quality, 'personal factors' & research contexts	S: The Quality Involvement questionnaire could facilitate reflection on the PPI process L: The model & its development is unclear
Mosavel et al (2005)	50	Community participatory research in south Africa	focus groups & informal interviews	Working with multiple stakeholders offered learning points fundamental to useful health promotion	S: Large and diverse sample from the community L: Confusing where PPI ends and participation in the research starts

Author & Year	Citations	Focus of the paper	Methods	Main findings	Strengths and limitations
Newell & South (2009)	46	The experiences of Lay researchers	Qualitative interviews	Overall involvement had a positive impact on the self-esteem, skills level and social awareness of researchers	S: Findings are supported by evidence from the lay researchers as opposed to perceptions of the researchers (common in other papers). Some negative impacts were also identified L: Interviewer was linked to the project so reporting of negative impacts might have been affected. Interviews only conducted at one time point so recall bias might be an issue
O'Donnell & Entwistle (2004)	20	Why and how research funders do PPI.	Postal survey & Focus groups	42 of 69 research funders have PPI, motivations and barriers	S: Mixed methods. L: No information on data analysis
Oliver et al (2008)	33	Developing and describing a conceptual framework for PPI	Literature review & reflections	PPI should be categorised by the types of people involved, the degree of public involvement and the initiators of the enjoyment	S: Combines components of other frameworks L: Usability of framework and details on its development
Popay & Williams (1996)	199	Lay knowledge in public health research	Discussion	Importance of lay knowledge to improve public health research	S:Takes a philosophical stance L: Sweeping statements
Renedo & Marston (2011)	N/A	Representatives' identities and social representations of PPI.	Cross sectional ethnography	Contradictory discourse in professionals understanding of the role of representatives.	S: Evidence based, highlights the contradictory discourse L: Unclear when drawing on professional or Involvement data
Rhodes et al (2002)	8	Researchers & representatives perceptions on a PPI consultancy group	Reflections	Motivations for involvement, value to researchers and representatives, Need for training, 6 key factors for effective PPI	S: Jointly written, shows both perspectives L: Evidence bases and analysis methods is vague/ anecdotal

Author & Year	Citations	Focus of the paper	Methods	Main findings	Strengths and limitations
Rummery (2009)	8	PPI in health service development & provision	Literature review	Some limited evidence of improved outcomes, little sig involvement, mostly collaborative	S: looks at challenges as well as benefits L: Very specific focus, detail of analysis, usability
Schulz et al (2001)	42	longitudinal research-community partnership	Interviews	PPI impacted research from prioritisation to dissemination and benefited community relations	S: Evidence of impact, relatively large sample size L: Exact sample size unclear, focused analysis, limited account of challenges
Simpson & House (2002)	123	PPI in delivery and evaluation of mental health services	Literature review	Mostly used as service providers. Benefits not reported negatives, differences between professionals and representatives in same role	S: Only high quality research included L: Detail of both search and findings very limited
Staley (2009b)	44	Evidence of impact of PPI in the literature	Literature review	Limited evidence of impact. Most evidence is informal, consistency of benefits and costs. 9 areas of impact	S: Included grey literature as well as peer reviewed, used an inclusive definition of impact. L: Due to the breath of the report in places it lacks depth in terms of information and interpretation
Staley (2012)	N/A	Evaluation of PPI in the Mental Health Research Network	Interview	Great variation in the impact of PPI. Challenges to researchers, support needed and recommendations	S: Evidence based , recommendations, focus on professionals experience L: Lacking detail on the criteria for the sub set explored
Stevens et al (2003)	N/A	Overcoming the challenges of PPI in cancer research (linked to networks)	Discussion paper	Centralised coordination of PPI overcomes many of the challenges of PPI	S: Raised some explanations for tokenism. L: Hard to tell what is from their experience and what is based on the literature

Author & Year	Citations	Focus of the paper	Methods	Main findings	Strengths and limitations
Stewart et al (2010)	2	A framework for methods to address representatives and clinicians research priorities	Literature review	258 studies which draw on representatives or clinicians experience for priority setting. Only 9 obtained both	S: Highlights the need for professional perspective in conjunction with representatives' views L: Framework does not match purpose. Does not discuss the priorities/ perspectives as the title suggests
Stickley (2006)	48	Power relationships in Mental health related PPI	Discussion paper	That patients now have power but need to establish it within the system	S: It explores the relationship between policy and practice L: While stating that it takes a 'realist' perspective and thus generating new information no new salient issues are raised
Telford & Faulkner (2004)	43	Motivations and barriers of PPI in mental health research	Discussion paper	Ideological differences are the main barrier to PPI	S: Raises importance of gray literature L: Sets itself up as a literature review but isn't. Does not justify 'motives'
Telford et al (2002)	37	Quantifying level of PPI in research (in a NHS region)	Survey	13% doing PPI. Confusion between collaboration and consultation	S: Evidence of level & type of PPI L: NHS trusts only
Telford et al (2004)	43	Achieving consensus on indicators of 'successful' PPI	Delphi process	8 principles of 'successful' involvement	S: Consumers and researchers involved in the DS, does not differentiate between successful and impact L: some principles may be difficult to put into practice/ access
Terry et al (2007)	37	Description of a advocacy groups role in genetic research	Discussion paper	Advocacy groups accelerate the speed of research	S: Shows how PPI can be used in Basic science L: Anecdotal evidence
Thompson et al (2012)	N/A	How representatives legitimise their knowledge	Ethnography	In addition to their experiential expertise representatives legitimise their credibility though a range of strategies	S: Evidence based, representative focused L: Context specific

Author & Year	Citations	Focus of the paper	Methods	Main findings	Strengths and limitations
Thompson et al (2009)	49	Health researchers attitudes to public involvement	Qualitative interviews	"differing constructions of public involvement in health research, the motivating factors an feelings of apprehension"	S: The range of interviews. Exploration of the Researchers Apprehension L: telephone interview combined with known 'pro PPI' positioning of researcher may have affected findings
Trivedi & Wykes (2002)	43	Reflection on experience of PPI in research	Discussion paper	PPI leads to longer research process, but a better research design and content	S: Gives practical information for others involved in PPI L: The 'qualitative' methodology is not explained neither is their approach to PPI
Viswanathan et al (2004)	313	Review of 'community-based participatory research- (CBPR) evidence	Literature review	Essential elements of CBPR, benefits and challenges, variability in type of involvement. Disadvantages not often reported	S: Looks at all aspects of process including funding (very few others look at this), process and evaluation L: N/A
Van Staa et al (2010)	N/A	Chronically ill adolescents as co researchers	Evidence based/ discussion Paper	Involvement feasible and appreciated by researchers and adolescents. Peer interviews lacked depth, difficult to main involvement of the chronically ill	S: Provides both benefits and challenges L: Does describe how they evaluated the different groups expresses
Walmsley (2004)	66	To reflect on past research that involved PPI in Disability research and draw out lessons learnt	Discussion paper	Issues of process, accountability, representation, and added value need to be considered when doing PPI	S: Makes a balanced argument by highlighting some of the difficulties of PPI as well as the benefits. Shows the importance of 'context' in PPI L: Based heavy on the authors' reflections limited evidence for findings. No justification for the choice of examples drawn on. Concludes the findings can be used in practice but does not say how

Author & Year	Citations	Focus of the paper	Methods	Main findings	Strengths and limitations
Walter et al (2003)	36	Effect of 'research impact' though partnerships a cross-disciplinary review	Literature review	Taking the challenges into consideration partnerships have the potential to increase research impact	S: While not a traditional systematic review the data were collected in a structured and thorough manner L: Does not identify or differentiate between the 'conceptual frameworks'
Ward et al (2009)	61	Researchers perspectives on PPI in health research	Qualitative interviews	The 'Know-do gap' researchers agree they should do PPI but don't	S: Strong evidence to support findings from a relatively representative sample. L: Only looks at the issue from one perspective.
Weinstein (2006)	46	Comparison of a PPI lead and a top-down lead service evaluation	Document analysis	PPI evaluation resulted in a higher response rate, more insightful data	S: Comparison across two models within one context L: did not allow for participants to reflect on experience
Wyatt et al (2008)	N/A	Evaluation with a focus on impact of PPI in LPCSP	Multi-method Case study	Description of involvement in the programme. Consumers impacted multiple aspects of the research process	S: Mixed methods, extensive data, multiple perspectives L: Retrospective

Appendix 2. Interview extracts

Extract one: Matt. Representative at comparator epilepsy network (Full interview 49.34 minutes, conducted face to face)

Matt Yeh, you know and so I think you know, hopefully it will make a difference for you as well you know what I mean, which will be good and that should be good for everybody. So, more of it.

Beth **Brilliant. Actually its really good because one of the questions I have got down here is, the benefits and positive impacts of people being involved in research, so you have already mentioned things like the names and the drugs and are there anything else?**

Matt I think, I probably, ur, when I first joined, urm, that sort of thing didn't particularly enter my head to be perfectly honest.

Beth **So why did you join?**

Matt Erm, I, I felt I wanted to 1) find out what it was about to be honest and ur see if my 10 penneth I could put in would anyone could relate to it an either help me or help them you know. I didn't really know. Urm, but you know the more when you sat down and listened to Jess and the way she went on about things and then bringing in um, doctors as well you know with it all which has been superb, you know and you do feel that you can put yourself over to how about things and they are actually listening to you and er, I do think that's good and I think that's excellent. And I you know, now we are sort of, the group is sort of definitely on a lift off, and now we have got even more funding for another 5 years, in this climate of, of, of cut backs and that's terrific. So we must be making a bit of a difference somewhere the way I see it, you know for that to happen, urm, and if its for the good and its for the benefit of everybody, then that is brilliant you know what I mean I was pleased to hear that we had um, funding for another 5 years which is fantastic, I was sad to hear that Jess is going but, you know, urm, you know she has got to get on with doing what she has got to do really I suppose and I am sure we will find someone else that is as, as enthusiastic as she is, and was, like, you know and yes that was good, that was the only sad point of the night I thought. Because she has been the mainstay about it I think really. Urm, It would be nice to get a few more people but as I say I don't know as like I said it's the first time I have been able to make it, I think people get there depending on what they have got on really, you know and so um, but as I said something very, very positive came out of it last night un, er, and I think that the mouthguard business I think try and take that forward because I think that is also a fantastic idea and that ul, will save a lot of people. Seeing it in, in the case of obviously nothing to do with rugby, nothing to do with epilepsy, but seeing it in the, how it helps rugby players when they take bangs and clink their teeth, you know that, thats is the, thats, you don't wear a mouthguard really to

save your teeth being knocked out 12. 55 it's the umm the concussion that you have got to stop, that is what they are mainly for. Um And when they are fitted properly you know you can have some serious bangs and you don't choke on these things un, and you know again that is something that we seem to be, we have picked up on, urm, and it will be great, to see if we can get that, going further because I think, that, would be a great help. I know Karl did say last night that you shouldn't put things in people's mouths but I do think that's more the, the case when people are actually maybe having an episode, having a fit. I do think with the mouth shield, if its fitted to the individual, its you are not likely to swallow it, you know. I, I don't know there is thousands and thousands of people use mouth shields playing sport and I am yet to hear of anybody, swallowing a mouth shield. You know an, you know and all you have got to do is you look at you know some of the players that play you know professional rugby players and things like that, that wear mouth shields, and the batterings they get like you know, and I, I think that's a pretty good test on how safe they are. You know you can never say never as I think I said last night, but I think that could be very good for people with epilepsy especially because they do suffer with teeth and gums and all the rest of it. An I think that would definitely be a positive, an that will help a lot of people. I really do think that will especially if they get urm, a lot you know some people can control their epilepsy rather well and they don't have fits from one year to the next which is brilliant, but you do obviously hear that people they have them umpteen times a day sometimes, at all ages urrm and I do think that something like that might help you know what I mean but obviously it won't stop the fits and everything else but it might help the inside of the mouth and it might stop that because you know when you bang your teeth together the back of your neck and the, the you know on the base of your brain it hurts a lot and I think you know we will see anyway, I think it will be a good thing to go down un, and look at it era bit more about it. Surprised no one else has come up with that really you know, and maybe they have I don't know but obviously we haven't heard of it, uurm, I am not saying that we should have heard of it, but for Karl not to have heard of it, next door he seems to know everything else Hahahahah, and obviously people I have worked with never really thought about it so I do think its could be something that will be good, definitely be good. So yeh, that's another good point that has come out of the RDG like you know. Urm, so yeh, that is another positive.

Extract two: Sue, Research coordinator, clinical trial (Full interview 49.34 minutes, conducted face to face)

Beth What is your understanding of the purpose of PPI in research?

Sue Ok.. what's my understanding erm... [pause 03] that we get input from... the patient, they have got the experience of what ever it is we are looking at the erm... the disease, the condition, so we can hear their voice to see what they feel and what their opinions are ((laughs)).

Beth You would be amazed the different answers people give,

Sue Yes is it ((laughs)).

Beth So it's about getting input from them?

Sue Yes

Beth Because they have got a different..

Sue Perspective, yes and they are the people with the experience aren't they?

Beth Yes. And, why do you think that's important or not?

Sue Because it's being, it's not being objective it is, it's not... it's actually being from within that person which we don't always do we look at it objectively don't we sometimes as researchers. Whereas we can actually get the voice of that person. And it just can inform us more can't it.

Beth And in any of your past jobs were you involved in PPI?

Sue Erm... I did, I did erm... I was quite interested in erm... when I did my psychology degree my dissertation was on erm... qualitative research erm... and social constructionism and stuff so I was quite interested in that side of things, yes. I did erm... yes I did my dissertation using the internet, ((laughs)) erm... I did it on narratives, taking narratives off the internet that people had written then did like thematic analysis and all that. Yes, ((laughs)). What did you do? Sorry I am asking you...

Extract three: Fred CCRN PPI network lead (Full interview 89.26 minutes, telephone interview)

Beth So if you were given the choice between a general member of the public, who had research experience or a person which had say experience of the disease, which...

Fred Yes, well erm... the pecking order as I say top of the list is the patient themselves. Which is another difficult area because erm... sometimes, the Society tend to say no you shouldn't, erm... you shouldn't involve people with cognitive impairment in discussion groups, because mainly because they argue that there is a chance these people will get upset. They will get confused about what is being talked about they might think people are talking about them, they might get erm... anxious, upset, erm... feel that they're you know not able to follow the conversation and feel upset by that, whereas I agree with that but I am slightly more biased towards saying well, have people with, so long as it's not too advanced cognitive impairment, the committee should be able to cope with people who ask for things to be repeated, and don't understand everything and you know the committee has to change to match the person erm... so it is not a big disagreement but it's there is a degree of difference there, so patients are at the top of the list but erm... it is not as simple as that. There is one analogy I always use

Beth oh?

Fred I always use this analogy but it's a bit like blind date you know Cilla Black and blind date, do you remember that? Erm...there is always 3 on those panels there is always 3 people there is, I always say there is the strong silent type, there is the kind of emotional Latin lover as they would call them and then there is the hilarious whacky one on the end who the audience find incredibly funny erm... and it tends to be those 3 people chosen in blind date and I think that you get those 3 types of people you get as reps on committees. And I think that the Professors who chair some of our committees wish all the lay people were the strong silent type, you know maybe a patient but not someone who is going to say very much in meetings. Erm... and but what we tend to get, is er... more of the second category you know the, the kind of passionate people erm... I call them Latin Lovers but the passionate people who erm... who, want to say a lot and erm... say it with strength and the Chairs are a little bit cautious about those and then of course nobody in theory wants the, the so called whacky one erm... who has very unusual views and unusual personality, erm... and you might find that erm... patients fall, are more likely to fall into the first category because you know they have got the direct experience but when it comes to a, a research committee they don't say very much, on some of our committees some of them say nothing throughout most of the meetings, erm... whereas if they were more passionate about it they might for example, if they were a member of the public, they might have less direct experience of the disease but they might be a better advocate.

Draft Interview Topic Guides ²⁰

Introduction

As outlined in the research protocol, in order to allow the individuals being interviewed an opportunity to discuss issues that are important to them a semi-structured interview approach will be implemented. This will involve a combination of pre-determined questions and ones that are raised during the interview. Some questions will be the same for each informant type, with the others being group/situation specific. The nature of the research will result in the questions developing over time, particularly where multiple interviews are conducted over a time span, with new questions arising as a result of earlier data analysis.

Below draft sets of possible research questions are listed, that might be asked of each of the informant types.

Case 1: PPI leads

In 2007 the National Institute for Health Research (NIHR) established a Comprehensive Clinical Research Network (CCRN) resulting in six topic-specific Clinical Research Networks and the Primary Care Research Network. Within these networks PPI was prioritised from the beginning, with designated funding attached to a PPI 'lead' role and mandatory in all networks. In order to understand the context within PPI is currently operationalised in UK health research, telephone interviews will be conducted with all of the PPI leads from the NIHR research networks.

Common Questions

- Please tell me about your current role.
- What is your experience of implementing PPI in this network?
- What (if anything) have you experienced to be the benefits/positive impact of PPI?
- What (if anything) have you experienced the challenges/negative impacts of PPI to be?
- What is your understanding of patient/ public involvement in research?

Case Specific Questions

- How does your network address PPI?
- Please describe the process you went through to get this model of PPI in place.
- What advice would you give to a new network developing its PPI process?

²⁰ This is the version submitted to and approved by the Universities ethics board

Case 2: UKERN

The UK Epilepsy Research Network (UKERN) was not part of the original research network funding and is a new network funded by the epilepsy research charities [and launched in Feb 2010]. The need for this network was identified from within the UK epilepsy research community itself, particularly as a means of facilitating large scale, multi-centre clinical trials. Like the other networks, one key component is that of PPI. Consequently, there is an opportunity to follow the process of PPI implementation within a research network from its inception, exploring how decisions are made around PPI and the consequences of these decisions.

The aim is to follow the development of the network PPI initiative for approximately 24 months. This includes (but is not limited to) attendance at full bi-yearly network meetings, interviews with key members of the network at multiple time points, tracking of the selection process, appointment and training of the PPI lay members, observation of the training processes and meetings of the Network management team and Clinical Study Groups (each of which will include PPI representatives).

Common Questions

- Please tell me about your current role in the UKERN.
- What is your understanding of patient/public involvement in research?
- Did you have any previous research experience before joining the UKERN?
- What (if anything) have you experienced to be the benefits/positive impacts of PPI?
- What (if anything) have you experienced the challenges/negative impacts of PPI to be?

Researcher/ clinician Specific Questions (time point one)

- Why did you decide to join the network?
- What is your opinion of the proposed/implemented model of PPI?
- What do you think are/will be the benefits/challenges of operationalising PPI in the network?

Patient/Public Specific Questions (time point one)

- Why did you become involved in the network?
- Have you been involved in health research before, either as a research 'subject' or a research partner?
- What to did you expect being part of the network to be like? To what extent have your expectations been met so far?
- What advice would you give to other patients/members of the public thinking about doing PPI?

Patient/Public Specific Questions (time point two)

- What is your opinion of the training you receive? (What if anything has been useful from the training? what other things if any would have been useful?)
- Please describe your experience of being in the Network
- Would you encourage other people you know to get involved in this way and why?

Case 3: Comparator Network

The comparator network has developed its own model of PPI with members meeting once every three months. For the purposes of this study, observations and interviews with key stakeholders will be conducted over a 6-month time frame. Inclusion of comparator network as a case study will allow for both a disease-specific comparison with the UKERN's PPI processes and insight into the operationalisation of the PPI agenda in a more developed and Central Government funded network.

Common Questions

- Please tell me about your current role in the WERN.
- What is your understanding of patient/public involvement in research?
- What is your experience of PPI?/ Did you have any previous experience before joining the WERN?
- What (if anything) have you experienced to be the benefits/positive impacts of PPI?
- What (if anything) have you experienced the challenges/negative impacts of PPI to be

Researcher/ coordinator Specific Questions

- Why did you decide to join the network?
- How does this network address the issue of PPI? (benefits/ challenges of the model)
- What was the process you went through to implement this model of PPI?
- What advice would you give to a new network developing its PPI process?

Patient/Public Specific Questions

- Why did you become involved in the network?
- Have you ever been involved in health research before, either as a research 'subject' or a research partner? (if yes, differences between being in a network and taking part in an individual research project?)
- Please describe your experience of being in the Network .
- What did you expect to happen before you joined the network?
- What advice would you give to others thinking about doing PPI?

Cases 4, 5 & 6 Clinical Trials

Within the time frame of the study it will not be possible to follow a single clinical trial from the application stage through to dissemination of findings. For this reason, three different clinical trials adopted by the UKERN will be the focus of individual case studies. Possible appropriate trials have been identified and their Principal Investigators (PIs) have agreed to the inclusion of their trials as case studies.

Common Questions

- Please tell me about your current role in this study.
- What is your understanding of patient/ public involvement in research?
- What is your experience of PPI?
- What (if anything) have you experienced to be the benefits/positive impacts of PPI?
- What (if anything) have you experienced the challenges/negative impacts of PPI to be?

Researcher/ clinical staff in clinical trials

- How have you tried to implement PPI in the context of this study?
- At what stage in developing the study did you begin PPI implementation?
- What have you found easy/difficult about involving patients/public in this study? Why?

Public, Patients in clinical trials

- Why did you decide to get involved in this research project?
- What if any are your past experiences of health research?
- Please tell me what it has been like to be part of this research

Appendix 4. Approach letter



Ann Jacoby, PhD
Professor of Medical Sociology

Email: ajacoby@liverpool.ac.uk
Tel + 44 (0)151 794 5602
Fax + 44 (0)151 794 5588

Division of Public Health
3rd Floor Whelan Building
Quadrangle
Brownlow Hill
Liverpool L69 3GB
United Kingdom

5th March 2010

Dear

Re: Request for help with PhD studies

I am a PhD student working with Professor Ann Jacoby, Professor Tony Marson and Dr Bridget Young at the University of Liverpool within the MRC Initiative for Clinical Trials Methodology (see www.liv.ac.uk/nwhtmr). My PhD studies are focussing on the broad question of patient involvement in prioritising and designing research, with reference to clinical trials.

I am particularly interested in the experiences of lay people involved in the research process and the impact their involvement has on both process and outcomes of research. I hope to follow the development of 'lay (including patient) involvement' in the UK Epilepsy Research Network and in a small number of clinical trials related to it. Taking an ethnographic approach, I plan to explore this issue from the viewpoints of all concerned, including not only patients and other lay members but also researchers and clinical staff. I will combine observations, attendance at research team meetings, reading of team meeting minutes, informal conversations and formal semi-structured interviews with a purposively selected sample of individuals, to develop an in-depth and holistic understanding of the issues involved.

Tony suggested that the bid you are currently developing would make a fascinating case study for my PhD, as it is at the developmental stage that lay members can, potentially, have the greatest impact. Should your study be subsequently funded, the opportunity to follow up its conduct in the early stages would also be invaluable.

If you would be willing to consider your proposed project as a possible case study, I and my primary supervisor, Ann Jacoby, would be happy to talk to you by phone or Email. Please be assured that the level of your involvement would be entirely open for discussion. Were you to agree to your work becoming a case study for me, you could be cited in any publications arising from my PhD studies. Thank you for your time reading this letter.


Best wishes,

Beth Deja

Email: E.Deja@Liv.ac.uk

Tel: 0151 795 5375

Appendix 5. Ethics approval


National Research Ethics Service
North West 3 Research Ethics Committee – Liverpool East

3rd Floor
Barlow House
4 Minshull Street
Manchester
M1 3DZ

Tel: 0161 625 7825
Fax: 0161 237 9427

16 April 2010

Professor A Jacoby
Professor of Medical Sociology
Division of Public Health
School of Population, Community & Behavioural Sciences
Whelan Building
The Quadrangle
Liverpool
L69 3GB

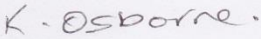
Dear Professor Jacoby

Further to email communication between Cathie Stokes and yourself regarding a proposed research project to be undertaken as part of the PhD studies of a student, being supervised by yourself, the information you submitted has been reviewed by the Chair, Mrs J Harkin, who has advised that ethical approval is not required.

Mrs Harkin has pointed out that she feels that ethical approval would have been in your best interests, but accepts that if you do not believe that published ethics approval research would be preferable, then there is no requirement for NHS REC review.

If you require any further information, please do not hesitate to contact me.

Yours sincerely



K. Osborne (Mrs)
Committee Co-ordinator – NW 7 REC

E-mail: kath.osborne@northwest.nhs.uk

This Research Ethics Committee is an advisory committee to the North West Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England



Ms Elizabeth Deja
School of Population Community and Behavioural Sciences
Waterhouse Building
Block B, 2nd Floor
University of Liverpool
Liverpool, L69 3GL

School of Population, Community
and Behavioural Sciences

Whelan Building (2nd Floor)
Quadrangle
Brownlow Hill
Liverpool
L69 3GB

T

23rd July 2010

Dear Ms Deja

I am pleased to inform you that the School of Population, Community and Behavioural Sciences Research Ethics Committee (REC) has approved your application for ethical approval. Details and conditions of the approval can be found below;

Applicant Name : Ms Elizabeth Deja
Ref. No : PCBS049A
Supervisor : Prof. A Jacoby
Title : "Patient and Public Involvement in Health Research Networks:
An Ethnography"
Date of email Approval : 16/7/10

The application was APPROVED subject to the following conditions:

Conditions

1. **Mandatory :** all serious adverse events must be reported to the School REC within 24 hours of their occurrence, via Dawn Holdman, School Administrator (d.holdman@liverpool.ac.uk) and the Research Governance Officer (ethics@liverpool.ac.uk).

This approval applies for the duration of the research. If it is proposed to extend the duration of the study as specified in the application form, the School REC should be notified. If it is proposed to make any amendment to the research, you should notify the School REC by following the procedure found on the ethics webpages at the following link;

<http://www.liv.ac.uk/researchethics/localpolicy.htm>

Yours sincerely

Dr I Fletcher
Chair of PCBS School Research Ethics Committee

Appendix 6. Participant information and consent forms



PARTICIPANT INFORMATION SHEET [UKERN example] Exploring Public and Patient Involvement in Research

You are being invited to take part in a research study. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve.

Please take time to read the following information carefully and feel free to ask if you would like more information or if there is anything that you do not understand.

Feel free to discuss this with your friends, relatives and colleagues if you wish. We would like to stress that you do not have to accept this invitation and should only agree to take part if you want to.

Who is doing the research?

Elizabeth Deja: PhD student in the Division of Public Health at the University of Liverpool.

Professor Ann Jacoby: Professor at Liverpool University will be supervising the research.

Dr Bridget Young: Reader and Director of Communication Skills at Liverpool University, will be supervising the research.

What is the purpose of the study?

The purpose of this study is to generate a detailed understating of public and patient involvement (PPI) in research, focusing on the experiences of the people who are involved. We are doing this because recent changes to government policy have led to an increase in PPI in research which will hopefully continue to develop. While there is now more known about how and why PPI *should* happen, less is known about how it *does* happen. We feel that it is important to understand the experiences of those involved to help future researchers and participants who will engage in PPI. This study will run until October 2012.

Why have I been chosen to take part?

You have been asked to take part in this study because you are involved in research involving patients or public as research partners and actively contributing to the process of doing health research. Your experiences are therefore very important to us.

Do I have to take part?

It is completely up to you. You only take part if you decide you want to. If you do decide you would like participate in the study you will be asked to sign a consent form to say that you agree to take part. If you decide later on that you wish to withdraw then you can leave the study at any time and you do not have to give a reason.

What will happen if I take part?

This research study will be asking you to be involved in a few ways and you can be involved as much or as little as you feel comfortable with:

In-depth interviews: You will be asked to take part in an interview, with the possibility of a follow-up interview if appropriate. You can choose to be interviewed on your own, or with your family/a friend present.

The interviews will involve you talking to the researcher about your experiences of being part of the UKERN. These interviews will last for as long as you would like to talk about your experiences- though it is expected that they will last approximately 45mins / 1hour. With your permission, these interviews will be audio-recorded.

Fieldwork and informal interviews: If you agree to it, the researcher may spend some time observing meetings you attend, such as the Patient Research and Development Group; and may chat informally with you about your experiences in general. From your conversations, she will take fieldnotes (a kind of research diary), which will be used to inform the research findings.

Feedback on findings: A selection of participants from across the research project will be asked to give their feedback on preliminary research findings to ensure that the information given is accurately represented. If you are happy to do this you may be contacted regarding this at a later time point.

Where will the research take place?

The interview(s) will be carried out at a time and place of your choice. You may like this to be your home, a public setting (e.g. a cafe), or Swansea University. It is up to you to decide. Also if you would feel more comfortable/ if it is more convenient telephone interviews can be arranged.

Are there any risks in taking part?

We do not expect there to be any risks or discomfort to be associated with participating in this research study. However, if you feel uncomfortable or distressed then you can stop the interview. You can leave the study without having to give a reason.

Are there any benefits in taking part?

You will be helping with a new area of research. Your experiences will help us to better understand how PPI happens and is experienced by those involved helping to improve the process in the future

What if I am unhappy or if there is a problem?

If you are unhappy or there is a problem, please feel free to let us know by contacting the lead researcher, Elizabeth Deja on 0151 795 5375 or by email: e.deja@liv.ac.uk, who will try to help. If you are still unhappy or have a complaint which you feel you cannot come to us with, then you should contact the Research Governance Officer, at Liverpool University on 0151 794 8290 (ethics@liv.ac.uk). If you contact the Governance officer please provide details of the name or description of the study (so that it can be identified), the researcher(s) involved, and the details of the complaint you wish to make.

Will my participation be kept confidential?

All the information that you give us will be kept strictly confidential. The procedures for handling, processing, storing and destroying the data will comply with the Data Protection Act of 1998.

This means that only the researchers will see what you have said. All the information which you provide us with during the study will be stored in locked filing cabinets or password protected computers. Anything about you, including any quotes which are used in the write-up of the study, will have your name removed and a different one put in place, so that you will remain anonymous.

At the end of the study the research data (consent forms, anonymised interview transcripts, fieldnotes, and your contact details) will be kept in locked filing cabinets and/or password protected university computers. The data will be kept for ten years.

Please note that if you did tell us something that meant you were in danger or could come to any harm, the researcher would have a duty to tell her supervisor about this.

What will happen to the results of the study?

After the study has finished, the results will be put together as part of the researcher's postgraduate research thesis and submitted for examination. The research material will be stored at the University of Liverpool. The research will also be published in academic journals and presented at conferences.

During the study we will ask you about your opinions on its findings, to get your ideas, comments and criticisms of what the research has found. If you wish you will be provided with a summary of the findings at the end of the study and you can have a copy of the final research report if you would like it.

What will happen if I want to stop taking part?

If you decide at any point that you no longer wish to be part of the study, then you can stop and do not have to give a reason for this. You can also ask for your data to be destroyed if you decide to stop being in the study.

How can I find out more?

Just get in touch with the researcher, Elizabeth Deja (PhD student) she will be happy to answer any questions you might have:

Tel: 0151 795 5375

Email: e.deja@liv.ac.uk

**Thank you for reading this
This information sheet is for you to keep**

CONSENT FORM

Exploring Public and Patient Involvement in Research

Researcher: Elizabeth Deja

**Please
initial box**

- | | |
|---|--------------------------|
| 1. I confirm that I have read and have understood the information sheet dated [DATE] for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | <input type="checkbox"/> |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my rights being affected. | <input type="checkbox"/> |
| 3. I understand that, under the Data Protection Act, I can at any time ask for access to the information I provide and I can also request the destruction of that information if I wish. | <input type="checkbox"/> |
| 4. I understand that quotes from what I say during the study may be used where necessary, on the condition that my identity will remain anonymous. | <input type="checkbox"/> |
| 5. I agree to being audio- recorded during the study interviews. | <input type="checkbox"/> |
| 6. I agree to the research data being stored. I understand the the anonymised data (interview trascripts and notes) may be shared with other researchers in the future. | <input type="checkbox"/> |
| 7. I agree to the researcher taking my contact details (name, telpehone number ect) in order to contact me during the study to arange interview times, ask for clarification or feedback. | <input type="checkbox"/> |
| 8. I agree to take part in the above study | <input type="checkbox"/> |

Participant Name

Date Signature

Name of Person taking consent Date Signature

Researcher Date Signature

[V2]

1 for Researcher, 1 for Participant (If required)

234

[20 July.10]

Appendix 7. Documents re. PPI in this thesis



University of Liverpool
Waterhouse Building
Block B, Second Floor
1-5 Brownlow Street
Liverpool
L69 3GL

Dear EARN Member,

I am a PHD student at the University of Liverpool looking at Patient and Public involvement (PPI) in Epilepsy research. My supervisors are Professor Ann Jacoby and Dr Bridget Young. We feel that with the increasing emphasis on PPI in research, it is important to understand how the process happens and the experiences of those involved. This will help facilitate useful and constructive partnerships between patients, the public and researchers.

As some of you might be aware, a UK Epilepsy Research Network (UKERN) was launched in February 2010, to help ensure that researchers across the UK are working together and looking at the important questions in epilepsy. Over the last year I have been working with Margaret Rawnsley and Monica Cooper from Epilepsy Action as they have been supporting the development of PPI in the Network. They have been kind enough to let me attend training events, meetings and interviews and have contributed to the design of my study.

For my study I am looking at the development of PPI in UKERN along with four other epilepsy- related research projects. I am doing this by looking at the documents produced, conducting interviews with everyone involved and observing meetings. In order to provide individuals being interviewed an opportunity to discuss issues that are important to them, I am using a combination of predetermined questions and ones that are raised during the interview. Some questions are the same regardless of the person being interviewed; while others are group/situation specific.

At this time, I am mainly writing to you to introduce myself as I am hoping that when I start to analyse the information people give me (in late 2011/early 2012), you might be willing to help me to develop interpretations of the data, given your own experiences of being involved in the research process. Separate to this (as the project is still developing) I would be grateful if you could let me know what you think of who I am interviewing, the questions I am asking and if my 'Plain English' summary of the project is clear (please see attached feedback sheet).

If you could please send any thoughts or comments back to Margaret Rawnsley by the 4th of January 2011 that would be really helpful. If you would prefer not to be involved please ignore this letter. Thank you for taking the time to read this. If you would like more information on this project please feel free to email or ring me.

Yours sincerely

Elizabeth Deja

Email: e.deja@liverpool.ac.uk

Telephone: 0151 795 5375

Feedback Sheet

There are four sections to this feedback sheet and a total of 13 questions. Please read over each section and give your feedback. Your responses will be combined with everyone else's and will be kept anonymous.

Section One

The 'Plain English Abstract' is a brief summary that I will use to help inform people who know nothing about this area, what the project is about. As such, it needs to be both clear and detailed, while still being concise.

Plain English Abstract

Since the early 1990s there has been a drive to increase the roles of patients as advisors in research. Over time this has become formalised into policy (DOH, 2001) resulting in a growth of interest into public, patient involvement in research (PPI). While there seems to be strong support for PPI in principle, implementing patient involvement in practice raises numerous questions. These questions include: what is meant by 'involvement' and 'patient'; what are the benefits, challenges and impacts of involvement on both the research process and outcomes, and for the people within it? Using an in-depth qualitative approach (observations, interviews & fieldnotes) this project aims to generate a detailed understating of PPI in research through eight separate case studies.

How easy do you think this abstract is to understand?

Very Easy Easy A little bit hard Very hard

How appropriate do you think the language is?

Not very appropriate Appropriate Very Appropriate

Please comment on any sections that you feel are unclear (and why) or need to be expanded

Please comment on what information (if any) you feel is missing:

Section Two

During this project I will be interviewing

- Patients and public involved in the UK Epilepsy research network (UKREN) or one of its linked projects.
- The researchers conducting the different projects
- Some of the Epilepsy specialists in the UK Epilepsy research network
- Coordinators of the research network and projects.
- A small selection of people working in the Epilepsy Drug industry

Do you think there are any other important groups of people that I need to talk to ensure that I have everyone's point of view (please circle)

Yes No.

If yes please say which group(s) you feel I am missing:

Please use the space below to make any other comments you have on the groups of people I will be interviewing:

Section Three

Researcher Questions	Patient and Public Questions
<ol style="list-style-type: none"> 1) Please tell me about your current role. 2) What is your understanding of patient/ public involvement in research? 3) Do you have any previous experience of PPI? (if yes please discuss) 4) How does your current research project address PPI? 5) What is your experience of implementing PPI in this research project? 6) What (if anything) have you experienced to be the benefits/positive impacts of PPI? 7) What (if anything) have you experienced the challenges/negative impacts of PPI to be? 8) What advice would you give to a new research project developing its PPI process? 	<ol style="list-style-type: none"> 9) Why did you become involved in the network? 10) Have you been involved in health research before, either as a research 'participants' or a research partner? 11) What to did you expect being part of the network to be like? To what extent have your expectations been met so far? 12) What advice would you give to other patients/members of the public thinking about doing PPI? 13) What (if anything) have you experienced to be the benefits/positive impact of PPI? 14) What (if anything) have you experienced the challenges/negative impacts of PPI to be?

In the above table are examples of the questions that I have been asking the researchers/ professionals and the Patient and Public involved in PPI in Epilepsy research about their experience of patient and public involvement in research. As you can see many of the questions are similar as I hope to compare across the different groups of people.

Do you think the wording of the questions make them easy to understand? **Yes/ No.** If 'no' please state the number(s) of the question and why you think it is not clear:

Do you think that these are useful questions to ask? Yes/ No. Please explain your answer

Please state any other questions that you feel it would be important to ask everyone about PPI?

Please state any other questions that you feel it would be important to ask either the researchers or patient and public about PPI (please say which group you are referring to)

Please use the space below to make any other comments you have on the questions being asked:

Section Four

Please indicate if you would be potentially interested in being involved further in this project by (for example) helping to develop the interpretations of the data and if you would mind being contacted about this at a later date

Yes, I would be interested to be involved in the future
No, I am not interested

If yes please give your name/ contact details (these will only be used for this reason and no other):
