

**An action research study of Patient and Public  
Involvement (PPI) in the NHS: How can PPI  
influence healthcare planning and decision  
making?**

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A thesis submitted for the degree of Doctor of Philosophy  
School of Nursing and Midwifery  
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**2010**

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### **Dedication**

This thesis is dedicated to Janet and my daughters, Brianne and Raechel, to thank them for their continual love, encouragement and support.

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## ABSTRACT

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**Background:** Patient and Public Involvement (PPI) has been in health policy for the NHS for the last 30 years and yet there is little evidence of their involvement influencing healthcare planning and decision making. PPI is a legislative duty for NHS bodies and yet there remains what is perceived as a ‘brick wall’ between the outputs of PPI and the outcomes in terms of influencing change (Commission for Health Improvement (CHI), 2004) .

**Aims:** To explore how PPI can influence healthcare planning and decision-making in the NHS. The objective was to explore, interpret and obtain a deeper understanding of the views and perceptions of staff within an NHS organisation and identify the attributes and enablers that facilitate PPI to influence planning and decision-making.

**Method:** This is an action research (AR) study, using semi-structured interviews and a critical document review as a pre-step, followed by the formation of an AR team following the cycle of steps.

**Results:** The yardstick of success against which PCTs were measured nationally and against which my colleagues and I measured our own practice, was one that celebrated outputs not outcomes and policy did little to persuade that PPI should influence planning and decision making. Staff and organisational rhetoric placed high importance on PPI, but change as a result was peripheral; however, robust project management through the AR process is a critical enabler.

**Conclusions:** New contributions to knowledge are provided by my proposal for an approach to enabling PPI in healthcare planning and decision-making using an AR project management methodology to ensure that measures of

success are set and repeatedly reassessed, and that follow through to change in healthcare service as a result takes place and the use of an AR methodology for this issue. The study has already directly contributed to national policy as findings were continually shared with the Department of Health.

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## **LIST OF ACRONYMS AND ABBREVIATIONS**

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ACHCEW	Association of Community Health Councils in England and Wales
CHC	Community Health Council
CHI	Commission for Health Improvement
CHAI	Commission for Health Inspection and Audit
CPPIH	Commission for Patient and Public Involvement in Health
CQC	Care Quality Commission
DH	Department of Health
EPP	Expert Patient Programme
ICAS	Independent Complaints and Advocacy Service
LINKs	Local Involvement Networks
NCC	National Consumers Council
NHS	National Health Service
NICE	National Institute for Clinical Excellence
NSF	National Service Framework
OSC	Overview and Scrutiny Committee
PALS	Patient Advice and Liaison Service
PCG	Primary Care Group
PCO	Primary Care Organisation
PCT	Primary Care Trust
PPIF	Patient and Public Involvement Forum
PPG	Patient Participation Group
PPI/PI	Patient and Public Involvement/Patient Involvement
SHA	Strategic Health Authority
WCC	World Class Commissioning
WNPCG/T	West Norfolk Primary Care Group/Trust

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# CHAPTER 1: INTRODUCTION

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*"By involving users and carers during planning and development, there is less risk of providing inappropriate services and more chance of services being provided in the way people want them"* (Department of Health, 1999a:3).

## 1.1 Introduction to the topic

Despite a legislative duty upon all NHS bodies to involve patients and the public in the planning and decision-making processes around the services they provide and commission (Parliament, 2007), changes in healthcare are not being made as a result (Picker Institute Europe, 2009). It is as if there is a 'brick wall' between the outputs of patient and public involvement (PPI) activity and any influence on outcomes (Commission for Health Improvement (CHI), 2004:11).

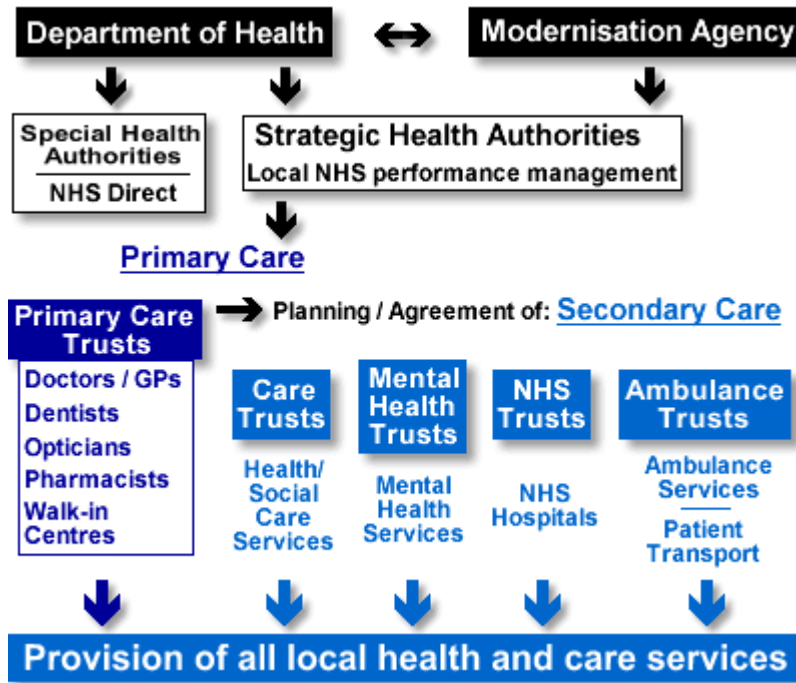
The challenge for NHS organisations and the rationale for this thesis is that it is the duty of NHS bodies to implement the content of the legislation, however a wealth of research and data indicate that although there is a great deal of PPI activity, the influence on planning and decision-making is minimal and there is little or no change to health services as a result.

This is an issue of particular interest to me, as my job for over 10 years has been to implement the PPI legislation within a Primary Care Trust (PCT). I believe passionately that the views of patients, carers, users and potential users of a service should have enough influence to affect improvement in healthcare service commissioning and delivery. I believe that it is possible for the NHS to embed PPI into everyday business and to be able to demonstrate the difference

or impact it has made. It was with this in mind, and my desire to improve my practice (McNiff, 2002), that I was inspired to research what it would take to enable effective PPI within a PCT.

Several PPI toolkits are available (Wilcox, 1994; Barker et al., 1999; Department of Health, 1999b; NHS Wales, 2001; Department of Health, 2003e; Involve, 2005; Roach, 2005; Andrews et al., 2006; Pacesetters Programme, 2008; South Central WCC Collaborative PPI Programme, 2008) on how to carry out PPI activity and the advantages and disadvantages of the various techniques. This study does not seek to replicate that work and it should be noted that there is little in the toolkits to address the issue of influence on healthcare planning and decision-making as a result of the PPI activity.

This study pays particular consideration to the implications of managing public involvement within the changing environment of healthcare commissioning (see figure 1.1 below for the structure of the NHS at the time of the field work from 2005 to 2006), beginning with the policy context from health watchdogs in the 1970s to the legislation and duty to involve the public in the 21<sup>st</sup> Century. It is shown that, although there has been national policy and legislation throughout the years, at the time of the field work and currently, commentators and regulators alike have identified that the outputs from the activity of PPI provides little influence on healthcare commissioning planning and decision making.



**Figure 1.1: Structure of the NHS in 2005** (NHS Connecting for Health, 2005)

## 1.2 Research question

The literature base on the topic of public involvement is vast (Ridley and Jones, 2002). However, it will be shown in Chapter 2 that much of the focus is on the patient perspective, the extent of user involvement and the use of public involvement techniques and the need for change in service delivery (Anthony and Crawford, 2000; Nicolson, 2000; Crawford et al., 2002; National Consumer Council (NCC), 2002b; Thompson et al., 2002; Birchall and Simmons, 2004; Farrell, 2004).

This research is important on both theoretical and practical grounds:



- I. The neglect of the specific research question by previous researchers.
- II. Relative neglect of using an action research methodology by previous researchers to investigate this issue. The methodology is justified in Chapter 3.
- III. Usefulness of the application of the research findings in influencing national policy and local action, i.e. enabling NHS organisations to respond to the needs and views of their publics.

Patients and the public were not included in this study as the literature review and previous research in this area has demonstrated that patients are participating in PPI activity, but the 'brick wall' occurs at the organisational stage where NHS organisations are required to respond to and act on those views. Ergo, it is the views of the staff and the issues of the organisation that need to be explored.

Although located in a particular context, at a specific moment in time between 2004 and 2006, the issues continue to have relevance today as the brick wall between PPI activity and change as a result remains (Picker Institute Europe, 2009).

Commentators and regulators alike still report seeing no evidence of PPI outputs in PCTs leading to change or improvement in healthcare services as a result. There appears to be an insurmountable brick wall.

This issue can be captured in the following (Table 1.1):

PPI activity	<b>Brick Wall</b>	Changes in health care service or delivery
Outputs	<b>Attributes and enablers</b>	Outcomes

**Table 1.1: The research issue**

In broad terms, therefore, the gap in knowledge and the question addressed in this research is:

**How can PPI influence planning and decision making in healthcare commissioning?**

This research focuses on the staff viewpoint at all levels in the organisation as to the extent to which responding to PPI had become a mainstream activity in planning and decision-making within my employing PCT.

Therefore, by exploring staff attitudes, the commitment of the organisation and other factors affecting the implementation, the study aimed:

1. to investigate to what extent the PPI policy had been put into practice within an NHS organisation;
2. to analyse the extent to which any PPI activity had influenced planning and decision-making;
3. to explore staff values and beliefs regarding involving patients and the public within said organisation;

4. to investigate the extent to which staff within the NHS organisation believed changes or improvement to healthcare services had been made as a result of PPI activity; and
5. given the analysis of the above, to consider and identify what the attributes and enabling factors are that facilitates PPI that influences healthcare planning and decision-making.

### **1.3 Why have I chosen this topic?**

It was within this environment of PPI activity not influencing health outcomes that I was the Public Involvement Manager (PIM) within West Norfolk Primary Care Trust (WNPCT) and had been in the role since its conception in 1999. The role of PIM was situated within the Modernisation Directorate and I answered directly to the Deputy Chief Executive. When PCTs were reconfigured in 2006, I secured a role as Associate Director of Communications and Patient and Public Involvement in the new amalgamated PCT; NHS Norfolk. In 2009 I was made a full Board Director with PPI in my portfolio and a team of staff delivering PPI within the PCT. It has been shown that there continues to be a 'brick wall' between PPI activity and change or improvements to healthcare services as a result and, therefore, the learning from this research remains as relevant to my work practice now as it did when I first began this journey in 2003-4.

The impetus for this research was derived from my own interest and experience in the field in anticipation that the study would provide practical knowledge of which I could take advantage in work practice (McNiff et al., 2003). In my own practice I was aware of the need to ensure effective PPI and I was, and continue to be, passionate in my belief that it is necessary and possible for the outputs of PPI research to directly influence service improvement. At the time of this study (2004) I believed that my own practice, lauded nationally as good

practice, was doing just that. For example, I received awards for my work and was approached on numerous occasions to guide other PCTs on how to do PPI, as is shown later in the analysis of the document review in Chapter 5. I had the general idea that if I could hold up each brick in the wall and examine why it was there and show how it could be overcome, the brick wall would be demolished. The learning and insights from my research would then be used to improve practice for other PPI practitioners and they would benefit from my lead. High on my personal agenda, researching how my own NHS organisation could enable PPI that influences planning and decision making, would also provide the opportunity to further improve my own practice (McNiff, 2000; McNiff et al., 2003).

In addition, as the researcher I was directly involved in writing the national guidance notes on the patient and public involvement legislation with the Department of Health and therefore had direct opportunity to influence national strategy and policy.

In my role in WNPCT I was expected by my employers to be an expert in involvement techniques, skilled at ensuring that participants in patient and public involvement 'research' have their say and that their contribution was valued. I was also expected to provide analysis and insights into the views and experiences of participants to help influence planning and decision-making. Facilitating focus groups, designing and implementing surveys and interviews were standard methods I used in my day-to-day business. In addition, involving people in decisions that affect them and working collaboratively is core to my personal values. I expand upon my own role within the activity under discussion and my personal preconceptions, challenges and struggles in the section on reflexivity (Chapter 8).

My background is in journalism and communications, and I am experienced in interviewing, building rapport with interviewees and writing for a range of audiences. I have written for local and national newspapers and magazines

where I must write in a clear, concise and engaging manner according to the needs of the target audience, which may be patients, readers of a particular newspaper, or people I need to encourage or entice to become engaged in an activity. My training is also in communications, listening skills, facilitation skills, and market research in its simplest sense of using a range of techniques to understand consumer views, needs and wants. In addition, I have been a member of a range of healthcare consumer groups; including five years as Chairman of the local branch of the National Childbirth Trust; working for the British Red Cross Home from Hospital Service preventing readmission to hospital; and for a small local support group for parents with a disability. During that time, I was involved in promoting the healthcare causes of the groups and attempting to influence decision-making at a local and national level.

WNPCT, my employing organisation at the time of the field work (2004 to 2006) was used as the focus for the research and it will be shown that this PCT was perceived to be of significance nationally within the field of PPI at that time. Although this may suggest that the PCT is unique, it is shown in the document review that in terms of PPI leading to change, WNPCT experienced the same 'brick wall' as other PCTs. The PCT is not anonymised for the purposes of this study, as my employing organisation supported the research and signed the relevant ethics forms. However, participants are anonymous, in keeping with the ethics approval.

In order for me to undertake this study, and prior to applying for ethics approval, it was necessary to have discussions with the key stakeholders, which comprised of the senior leaders within the PCT, to negotiate my study leave and funding. During that process I shared with them my initial thoughts for the study and the gap I had identified in understanding of how to facilitate PPI that influences planning and decision-making. There was general agreement that my concern was shared and approval was granted.

In addition, the NHS Modernisation Agency (Sang, 2004c), Norfolk, Suffolk and Cambridgeshire Strategic Health Authority (SHA) (Hague, 2004), and the DH (2006) supported this piece of research as “filling an important gap in our learning about the implementation of PPI policies” and in how to bring about a culture change that supports PPI (Sang, 2004c:3). It might be expected, of course, that the statutory bodies responsible for devising and performance monitoring the policy would have a vested interest, however this does not devalue the expressed interest in learning from this research.

With my own interest in the subject and agreement from my organisation, the Strategic Health Authority and the Department of Health concluded that there was merit in researching this issue in order to potentially address the issue.

The reconfiguration of PCTs was implemented during the research and has an impact on the AR project where the focus moves from the ‘bricks in the wall’ to fears for the future for both the individuals and the organisation. Whilst limiting the extent of the AR project in examining the actions in more detail, it nevertheless provided insight into how organisational change can distract practitioners away from improving healthcare to looking more inwardly.

## **1.4 My approach to the research**

I applied to undertake a PhD at the University of East Anglia in September 2003. I explained to my primary supervisor the issue I wanted to explore and why, and my thoughts on the approach I wanted to take. He informed me that action research would most likely suit my needs and that I should consider this further. The study focused on the PCT staff and their approach to implementing PPI within the organisation and it will be shown that this exploration is best suited to a qualitative methodology concerned with gaining insight into the individual’s perspective. In addition, I aimed to research my own organisation and my own practice, as an ‘insider researcher’. My own

passion for the subject and the integral role I played in implementing PPI within my own organisation could not be ignored. I was therefore neither value-free in my perspective, nor objective in my analysis. Instead, I needed to apply my practical and applied knowledge and put theory into practice (Habermas, 1973; McNiff et al., 2003).

Following up the suggestion from my primary supervisor and after extensive reading and careful consideration of the practical options available to me (see Chapter 3), I decided action research provided an appropriate framework within a qualitative methodology with which to explore the research issue. Broadly based on Kemmis and McTaggart's (1997) action research cycle, the pre-step comprises of a reconnaissance of public involvement in the form of a critical document review of the research site and semi-structured interviews with members of staff in the organisation. The aim here was to establish an understanding of current practice and put the research into context (see Chapters 5 and 6). An action research team was then formed, with participants identified from previous PPI projects that had not led to change (see Chapter 7). AR Team reflective diaries were maintained by the participants who shared some of their excerpts within the group, but also submitted their diaries to me to be included as data. In addition to the AR Team reflective diary, I also maintained my own reflexivity journal (not to be confused with the AR Team diaries) throughout the doctoral study. Reflexivity can be defined as:

“sensitivity to the ways in which the researcher and the research process have shaped the collected data, including the role of prior assumptions and experience” (Mays and Pope, 2000).

My reflexivity, thoughts, feelings, challenges and struggles are discussed in Chapter 8.

The issue of defining rigour is discussed at length and I identify a blend of both traditional and more constructivist criteria of credibility and validity, transferability and generalisability, dependability and reliability and confirmability and objectivity, against which to establish the rigour of my study (Lincoln and Guba, 1985; Miles and Huberman, 1994).

## **1.5 Outline of the thesis**

The research question is posed in relation to my own practice and that of my organisation. I am an insider researcher and I therefore describe the process that I undertook to carry out this research.

Chapter 2 provides a critical chronological and historical review of public involvement policy and research from the patient voice heard via a ‘health watchdog’ organisation, the Community Health Council, through consumerism to the advent of PPI. I consider the Government’s rhetoric, which focused on involving the public systematically, using a range of PPI techniques and ensuring that ‘hard to reach’ communities and individuals are engaged. I note that there are a plethora of strategies, policies and toolkits focusing on the processes and activity of PPI, and yet it appears that the process of listening to the views of patients is not influencing planning and decision making for improvement of health services as a result. Bringing the review further up to date, the chapter considers the changing environment of the PCT in terms of ‘Commissioning a patient-led NHS’ (Department of Health, 2005a) and touch upon the anticipated changes from the NHS White Paper ‘*Equity and excellence: liberating the NHS*’ (Department of Health, 2010). I also include the local policy development within WNPCT. I finish by documenting the reconfiguration of WNPCT with four others in the area, which took place during the time of some of my field work in 2006.



Chapters 3 and 4 describe the research methodology, the justification for this approach and explain the processes and methods for carrying out the research. I also provide sections on the rigour of the research, details of the ethics approval and information regarding the chosen sample. I explain that I am an insider researcher, examining my own practice in order to better understand what I do and how I can make improvements within my own practice and within my own organisation of West Norfolk Primary Care Trust (WNPCT). I discuss my decision to use an action research methodology and Kemmis and McTaggart's (1997) action research cycle of a pre-step, then plan, act, observe, and reflect. I describe how the critical document review and the findings and analysis of the semi-structured interviews provide the pre-step and how an action research team will then be formed to examine, through action, what the NHS can do to enable PPI that influences planning and decision-making.

Chapters 5-7 present the data analysis; firstly, providing a critical document review of the site chosen for the research, secondly, the findings and analysis of the semi-structured interviews, then thirdly, the findings and analysis from the action research team. In Chapter 5, I provide further contextual information about the site of the action research, WNPCT, in addition to the policy context in Chapter 1. A scrutiny of the patient and public involvement activities over the years since formation of the PCT is provided, highlighting the prolific PPI activity, but identifying little evidence of change as a result, in line with national findings about PCTs in general. I also describe how WNPCT received accolades and praise as a best practice site for PPI, demonstrating the measures of success for PPI that were used both locally and nationally. In chapter 6, I provide further contextual information and analysis, with the aim of understanding not only what staff thought of PPI generally, within WNPCT and within their own practice, but also why they held those views. I make a vital conclusion that supported the findings in the critical document review – that change resulting from PPI was peripheral, that the measures of success were based on exciting and inclusive events and activities, rather than health outcomes and that the barriers to PPI and the enabling factors identified are

again no different to findings from national research. In chapter 7, I provide a thematic analysis of the action research meetings, where participants describe a lack of follow through on PPI activity and recognise themselves as a brick in the wall preventing change as a result. The participants highlight that by following the action research cycle, change is brought about, which leads them to conclude that robust project management is the solution to enable PPI that influences planning and decision-making.

Chapter 8 describes my own journey throughout the doctoral study and provides insight into my personal subjectivity, challenges and struggles.

Chapter 9 identifies my contribution to new knowledge, offers suggestions, conclusions and recommendations for research, policy and practice from the research findings. I conclude that there are six key steps to enable PPI to lead to change:

1. set and agree measures of success, using the measures to ensure action and continually evaluate and revise to ensure the measures remain appropriate;
2. use a project management process based on action research to ensure follow through;
3. involve patients and carers in the project management, as an action research methodology supports the participatory process;
4. agree the plan of action for patient and public involvement, regardless of whether the PPI is done 'in-house' or is commissioned out to a research company;
5. ensure the output of an independent thematic analysis of the PPI is evaluated and reflected upon as part of the action research project;
6. revise the plans to reflect the changes required, as identified in the PPI analysis report.

## 1.6 Definitions

For the purposes of this thesis, Table 1.2 below provides some definitions for the terms used when discussing patient and public involvement.

Term	Definition
“Patient(s) and public”	Used to include patients, users, carers and the public.
“Patients”	Refers to those people who are currently using health services.
“Users”	Refers more generally to people who make or have made use of health and related services that contribute to their health.
“Carers”	Refers to people who care (in non-professional circumstances) for those who are ill or disabled (usually members of the family or friends).
“Public”	Refers to the general public/citizens.

**Table 1.2: Terms and definitions.** (Department of Health, 1999a:23)

Further definitions of PPI are provided in Chapter 2.

## 1.7 Chapter summary

In this chapter I have laid the foundations for the thesis. I introduced the research problem and research issues. Then I justified the research, presented definitions, briefly described and justified the methodology, the report was outlined, and the contents of the chapters summarised. On these foundations, the thesis can proceed with a detailed description of the research and the findings.

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## CHAPTER 2: POLICY CONTEXT

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### 2.1 Introduction

In Chapter 1 described the foundations for the thesis; in this chapter I present a critical review of the national literature and policy and local policy development and provide a context for the research.

In order to identify relevant literature for the critical literature review, a search strategy was devised, informed by my research questions. The purpose here was to assess the literature, not to provide a systematic review. The search was carried out using electronic databases, using MEDLINE, PubMed and a more sweeping search via Google. To increase the likelihood of finding relevant materials, I used the search terms ‘consumerism’, ‘public involvement’, ‘user involvement’, ‘patient and public involvement’ and ‘patient participation’. To narrow the search, I identified Boolean connectors, which I linked with the original search terms such as patient involvement and public involvement indicated above with ‘health’, ‘NHS’ and ‘Primary Care Trust’.

Based on the results, I used Athens to electronically download full copies of the articles, ordered books via the University library and searched my own extensive personal library of books and documents. I then categorised the documents into chronological and sequential themes according to the milestones of national policy development. By reading the documents, potential further reading was identified and, where appropriate, downloaded. I did not screen in terms of year, but considered the content for background and relevant context.

I therefore begin my critical literature review with an attempt to define PPI then follow a chronologically ordered history from consumerism in the 1970s through to PPI and the current legislation in 2010.

*“We’ll open him up from here to here” (to medical students) “...don’t worry, my man, this doesn’t concern you at all.” (to patient). Sir Lancelot Spratt in Doctor in the House (Gordon and Phipps, 1954)*

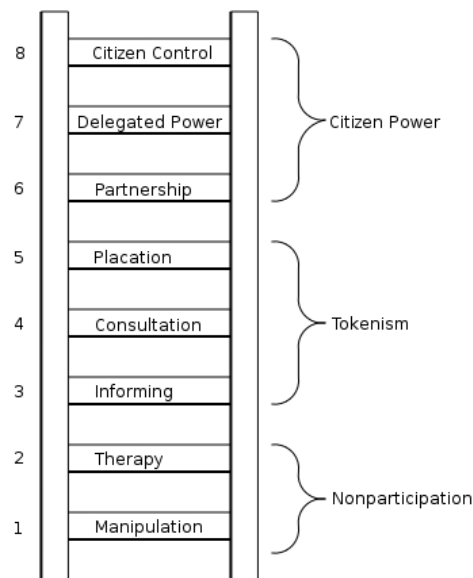
Patient and Public Involvement (PPI) in the National Health Service (NHS) is a theoretical and practical move from the patient being seen as a passive recipient of health care, as parodied above, to patients, carers, people who use services and the public being encouraged to be involved in, and influence, the planning and decision-making process around the services commissioned and provided within the local NHS.

PPI is “...a process for involving the public in the decision-making process of an organisation” (Roberts, 1995:4) and occurs “...when people are involved and influence decisions which are likely to affect them” (Leigh, 1988:115). Other commentators argue that to suggest that the ‘public’ can be identified as a single identity is false and that there are a number of different ‘publics’ (Roberts, 1995; Jakubowska and Crossley, 1999; House of Commons Health Committee, 2007a). They site those people that use a particular service or have a specific procedure, others who live in a certain area as residents or in communities, or are of a certain age, or those members of the public who have a specific interest.

PPI can be understood on two levels: at both the ‘individual’ level (involvement in their own healthcare decision-making) and at a ‘collective’ level, however this thesis concentrates on the ‘collective’ level - involvement that is meaningful, leads to action and occurs across a range of activities (NHS Executive, 1996). Patients and the public could be involved on a collective level at all stages of an improvement process within an NHS organisation influencing service delivery, provision of patient information, service design

and operational and management decisions. They could also be involved in wider local policy and planning, helping to shape commissioning processes, clinical governance and broader strategic issues (NHS Modernisation Agency, 2001a).

Researchers have considered the idea that there are further levels within collective public involvement. Arnstein (1969) suggested eight levels of a ladder of participation from manipulation and therapy at the non-participative bottom rungs, through tokenism to partnership, delegated power and citizen control at the top. (see Figure 2.1 below). This model focuses on the issue of who holds the power to make decisions, with only the very top rungs putting the power into the hands of lay people. It places an emphasis on the role of power in participation, highlighting information, consultation and placation as mere tokenism. The labels given to the individual rungs and the three themed categories suggest that the top of the ladder is ‘good’ and the bottom ‘bad’.



**Figure 2.1:** Arnstein's Ladder of Participation (1969)

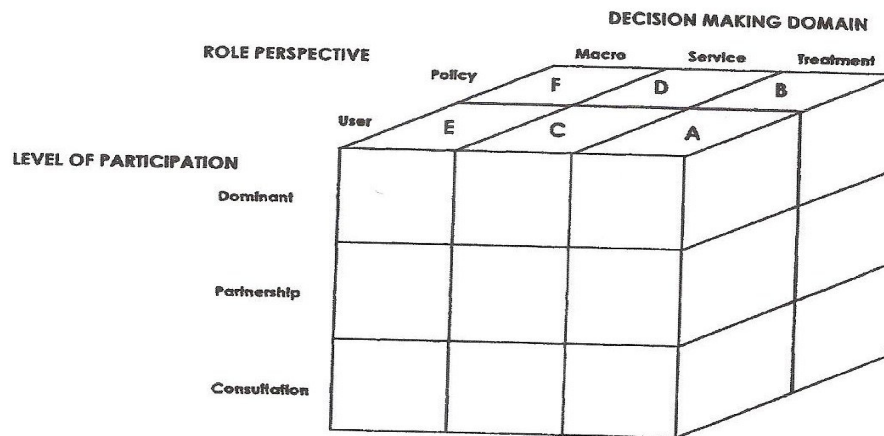
Since then, variations on Arnstein's ladder have been explored; Hart (1992) studied the ladder of youth participation, whilst Wilcox (1994) provided rungs of a ladder which moved from information and consultation through to acting together and supporting independent community interests.

Tritter and McCallum (2006) argue that Arnstein's focus on the power to make decisions and the hierarchical design is limiting and ignores other more complex issues involved, such as the methods used to involve participants, the issue of the numbers of people who have an interest in the subject and their involvement to a greater or lesser extent, and the problem of sustained relationships and evaluation. The authors suggest that to use a ladder analogy accurately would create a model that resembles more of a scaffold of interrelated ladders and levels of participation. Instead, they claim that their description of a mosaic of tiles, interconnected and related, better illustrates the interdependence of service users, citizens, communities and healthcare systems. They recommend that participation is evaluated cyclically to consider the impact on decision-making.

Charles and DeMaio (1993:893) identify just three rungs on the ladder of participation, categorising them as "consultation, partnership, and lay control." With the highest rungs of the ladder - lay control - providing greater public control in decision-making. They do not consider providing information to be decision-making, as the communication is one-way. Instead, consultation is the bottom rung, where people are able to give their views, but with potentially only limited influence on decision-making. Partnership, they say, suggests greater negotiation between the parties which provides greater opportunity for a balance in power and control. At the top of the ladder power and control is ultimately given to the lay individuals.

Taking this model one step further, Charles and DeMaio (1993:891) devise a three dimensional conceptual framework of lay participation in healthcare

decision-making (see figure 2.2). This framework depicts (a) three decision-making domains, (b) two role perspectives and; (c) three levels of participation. They claim the framework illustrates the confusion that arises in the different perceptions and understandings of the definition of patient or public participation and involvement. They also acknowledge limitations in the framework as, for example, it does not explore the various techniques and methods of involvement and consultation that add yet another dimension.



**Figure 2.2:** Dimensions of lay participation in health care decision making (Charles and DeMaio, 1993:891)

Forbat et al., (2009:2548) attempt to highlight four models of involvement from their study which have different “ideological drivers” (see table.2.1). They state each ideology brings about different methods and levels of participation, but query how germane these models are in reality.



<b>Who</b>	<b>What</b>	<b>Ideological driver</b>
Patient as consumer	Purchase of choice of service	Free-market economics
Patient as citizen	Policy and service planning	Social-democratic
Patient/partner as partner	Care practice	Experiential knowledge
Patient as researcher	Co-research	Emancipation and empowerment

**Table 2.1:** Models of involvement (Forbat et al., 2009:2548)

Wilcox (1994) suggests that different levels of participation are required for different circumstances and not necessarily a case of one level being ‘better’ than another. Charles and DeMaio (1993) state that determining the level of lay participation is an important pre-cursor to deciding upon the appropriate technique or method to be used. Waite and Nolte (2006) state there is no one clear conceptual framework or model of participation, while Cornwall (2008) says that the reality of PPI is more complex than the models would suggest and several levels or types can be seen in any single project. She takes this further and adapts a typology of power interests first identified by White (1996) (see table 2.2).

Form	What 'participation' means to the implementing agency	What 'participation' means for those on the receiving end	What 'participation' is for
Nominal	Legitimation – to show they are doing something	Inclusion – to retain some access to potential benefits	Display
Instrumental	Efficiency – to limit funders' input, draw on community contributions and make projects more cost-effective	Cost – of time spent on project-related labour and other activities	As a means to achieving cost-effectiveness and local facilities
Representative	Sustainability – to avoid creating dependency	Leverage – to influence the shape the project takes and its management	To give people a voice in determining their own development
Transformative	Empowerment – to enable people to make their own decisions, work out what to do and take action	Empowerment – to be able to decide and act for themselves	Both as a means and an end, a continuing dynamic

Adapted from White, 1996, pp. 7–9.

**Table 2.2:** A typology of interests (Cornwall, 2008:273)

There have been many studies considering the role of power in participation in general and PPI in healthcare (Pretty, 1995; White, 1996; Cornwall, 2008) and one of the key questions behind the driver for participation is ultimately “who has the right to make what health care decisions in whose interests” (Charles and DeMaio, 1993:883).

Alford (1975) identifies three main power interests in healthcare decision-making: the medical profession, managers and community populations. He claims that the structure of community participation is designed to ensure that effective decision-making cannot take place. He purports that there are power incentives to involve as many people as possible, all of whom have conflicting and opposing views, which make it impossible to reach a consensus. This, he

says, means that “all points of view will be heard but not implemented, save those of the interests who already hold power” (Alford, 1975:221). Furthermore, even those who originally embraced the idea of community involvement then become skeptical about its value and are less likely to support their involvement next time.

Alford (1975) later admits that many of his theories are speculation and hypotheses rather than fact; however more recent research upholds much of what he claimed (Baggott, 2004). Wilson (1999) suggests that democratically elected councilors in Local Authorities consider citizen participation as having the potential to usurp their role as speaking on behalf of the populace and thereby reducing or removing their power. Even with a process of involvement, ultimately managers have the power to decide upon the extent and parameters of the PPI (Anderson et al., 2005).

Since then, variations on Arnstein’s ladder have been explored; Hart (1992) studied the ‘ladder’ of youth participation, whilst Wilcox (1994) provided rungs of a ladder which moved from information and consultation through to acting together and supporting independent community interests. Wilcox suggests that different levels of participation are required for different circumstances and not necessarily a case of one level being ‘better’ than another.

Other researchers have asserted that what ‘involving the public’ means has never been sufficiently defined (Pietroni et al., 2003; Florin and Dixon, 2004). The Department of Health (2004e) argued on their website that:

*“Patient and public involvement is not just about structures – it is a cultural change. It is about empowering patients and the public to have a say and about people in the NHS working differently and listening to and acting upon the views of patients and the public. Patient and public involvement improves patients’ experiences of the NHS.”*

In 2009 the Healthcare Commission (Healthcare Commission, 2009:3) further defined PPI as:

*“A process through which patients, users of services and communities share their views and experiences with trusts, and work together to plan services. It covers how health services consult with, involve and participate with patients, users and the public and how they take account of people’s views. It also covers how trusts communicate with people, about they can engage with them, what people can influence, and what is done with their views and experiences.”*

Having attempted to define PPI, an understanding of how PPI systems evolved is needed to put current development into context (Baggott, 1998) and the use of a literature review to do this can serve a number of purposes. First, systematic reading identifies what is already known and published about the topic, which in turn highlights any gaps in the existing body of knowledge (Hart, 2003). Second, the literature review can help demonstrate how this new study has a place within the existing knowledge area without replication (Holloway and Wheeler, 1996). The aim of this chapter, therefore, is to critically examine the history of patient representation and consumerism and the present statutory duties placed upon every NHS organisation for PPI. In 2.1 I identify the search strategies used for this literature review. I first consider PPI from a national perspective, and then look more closely at a local level, within a PCT.

## **2.2 National policy**

The nature of the evolution of patient and public involvement is an area that has received varying attention during the last century, with researchers choosing different starting points and varying perspectives. Hogg (2009) outlines the rationale behind, and plots the development of, participation and consumerism from the 1960s active citizenship and the New Right, through the role of

complaints and advocacy of the 1980s and Charters of the 1990s to New Labour.

Roberts and Marshall (1999) suggest that mass public involvement is the result of increased education, 1960s liberalism and developments in global telecommunications. Others cite the reforms that created the NHS 'internal market' for the emergence of user involvement, but suggest that "progress has been limited" (Rhodes and Nocon, 1998:73). Thompson et al., (2002) talk of the World Health Organisation (WHO) leading the promotion of community involvement in healthcare since the 1970s.

Church et al., (2002:12) explain that increased participation reflects an attempt by government to "respond to the increasing and widespread view that the major institutions of society are unresponsive and unaccountable to citizens." Several authors cite participation as a means of addressing the democratic deficit (Harrison and Mort, 1998; Milewa et al., 1999; Pratchett, 1999; Baggott, 2004; Baggott et al., 2005).

Charles and DeMaio (1993:886) agree that increased education has been a key driver, claiming that the more informed people become about their consumer rights, the higher the "desire for greater public accountability in health care decision-making."

Many researchers and commentators have referred to the rationale for participation as one of fashion (Charles and DeMaio, 1993; Pretty, 1995; Pratchett, 1999), Charles and DeMaio (1993:883) identify three reasons for lay participation becoming increasingly fashionable:

1. *"A loss of faith in the legitimacy and superiority of professional knowledge as the key determinant of health care decision-making;*

2. *A redefinition of the appropriate role for provincial governments in local health care resource allocation decision-making; and*
3. *The desire to hold health care providers more accountable to the communities they serve.”*

There are schools of thought that suggest drivers for participation are from both a democratic and a consumerist perspective. From the former, greater participation would lead to improved accountability and a better understanding of the dilemmas involved in decision-making. From a consumerist perspective, economically, patient choice and an increased right to information and access helps enhance competitiveness between providers (Wait and Nolte, 2006).

Wilson (1999) suggests that the prolific activity serves merely to make organisations look modern and forward thinking and Hogg (2009:90) concludes that “there is little evidence that the NHS is more patient-centred as a result.”

Ridley and Jones (2002) offer a summary of key landmarks in the development of public involvement in the NHS from 1948 – 2001, Birchall and Simmons (2004) give a potted history of bureau-professionalism and market based relationships in user involvement within similar parameters, whilst Farrell (2004:6-7) provides a timeline highlighting the key policies for patient and public involvement from 1990, with the passing of the *Community Care Act*, (Parliament, 1990) through to 2003 and *Building on the Best – Choice, Responsiveness and Equity in the NHS* (Department of Health, 2003a). A further timeline has been provided from the 1970s to 2010 in Table 2.2.

**Table 2.2: Timeline of Patient and Public Involvement (PPI)**

<b>Date</b>	<b>Milestone</b>
1974	Community Health Councils (CHCs) and Association of Community Health Councils in England and Wales (ACHCEW) established
1989	‘Working for Patients’ (Department of Health, 1989) introduced concept of patients as consumers

1991	Patient Charter published (Department of Health, 1991)
1992	'Local Voice' stressed ensuring those who seldom have a say are heard and managing expectation (NHS Management Executive, 1992)
1996	'Patient Partnership' strategy promoted user involvement and ensuring services responsive to needs of patients (NHS Executive, 1996)
1997	Primary Care Groups/Trusts created
1999	'Patient and Public Involvement (PPI) in the New NHS' (Department of Health, 1999a) published mainstreaming PPI
2000	NHS Plan (Department of Health, 2000) introduced new processes for PPI – PALS, Patient and Public Involvement Forums (PPIFs) and systematic PPI
2001/02	Health and Social Care Act (Parliament, 2001) abolishes CHCs and introduces PPIFs and Commissioning for Patient and Public Involvement in Health (CPPIH), placing legal duty of PPI on NHS organisations
2004	Plans announced to abolish CPPIH
2004	CHI find a 'brick wall' between PPI activity and change in health services
2006	NHS Act (Parliament, 2006) consolidates section 11 of the Health and Social Care Act 2001
2006	DH announce intention to abolish PPIFs and replace with Local Involvement Networks (LINKs) (Department of Health, 2006a)
2007	'Local Government and Public Involvement in Health' Act (Parliament, 2007) further defines duty of PPI
2009	Research finds PPI still not leading to change (Healthcare Commission, 2009)
2009	NHS Constitution launched (Department of Health, 2009b)
2010	White paper 'Liberating the NHS' introduces GP commissioning and HealthWatch to replace LINKs (Department of Health, 2010)

**Table 2.2: Timeline of Patient and Public Involvement (PPI)**

For the purposes of this review, this section begins with the formation of Community Health Councils (CHCs) and the concept of patient representation, through to the introduction of consumerism and the legislation which replaced CHCs, and finally the current legislation and the challenges therein.

### **2.2.1 Representation**

From 1974, the 207 Community Health Councils (CHCs) in England and Wales were the one formal mechanism for giving voice to the concerns of patients and families (Hutton, 2000). The plans for CHCs were first established by the Conservative Government and outlined in the NHS Reorganisation Act in 1973 as a way of addressing the democratic deficit in the NHS (Parliament, 1973; Hogg, 2009) and the Act was already in force when the new Labour Government came into power in April of 1973. The role of the CHC was to act as patient advocates and public watchdogs to ensure that the patient's voice was listened to and heard and ensure complaints were dealt with (Baggott, 1998; Hutton, 2000; Baggott et al., 2005). CHCs were statutory bodies, which aimed to be representative and accountable and were to provide a new way of ensuring that NHS management listened to the needs of communities through representation (Hutton, 2000). Their remit included patient involvement and consultation, research and information, pressing for changes, offering help and advice and with a legal duty to represent the interests of the community in the NHS. Health Authorities, in turn, had a duty to consult CHCs when considering any 'substantial variations in service' (Hutton, 2000) though what this meant was never clearly defined, thus somewhat diminishing the value of such a power.

Each CHC comprised of between 18 and 24 members who were unpaid volunteers: half appointed by the local council; one third elected by local voluntary groups and organisations; the remainder appointed by the Department



of Health (Allsop, 1993:51). In addition, the CHC could co-opt people with specialist skills or a particular interest.

There was one CHC per District Health Authority with two paid officers per CHC, appointed by the Secretary of State and responsible for the management and administration. CHC meetings were held in public and members originally had rights to visit NHS properties and inspect them, the right to be consulted on any major changes in health-care delivery and the duty to work in the interest of patients (Hutton, 2000). There was widespread criticism of CHCs and a list of their limitations, such as lack of funding and paid officers, the question of balancing public representation while needing to retain successful relationships with local healthcare organisations, and the lack of power to influence (Leathard, 2000).

The Association of Community Health Councils for England and Wales (ACHCEW) was set up in 1977 to provide advice and guidance to CHCs and to represent CHCs at national level. There is very little objective material available regarding the impact the launch of ACHCEW had on CHCs or providing a voice for patients.

### **2.2.2 Consumerism**

In 1983 the now Conservative Government (since 1979) commissioned an inquiry into NHS management following over a decade of Labour Government and ruling. The resulting series of recommendations in the *Griffiths NHS Management Inquiry* (Department of Health and Social Security, 1983) (colloquially called the '*Griffiths Report*') referred to the 'consumer', rather than a patient, and advocated using market research techniques to ensure that a patient's needs and wants were understood. It stated that the assumption that these views could be obtained from the CHC was flawed (Allsop, 1993).

Some CHCs involved local people and worked closely with communities. Conversely, it was believed that members felt themselves to be a “quasi-representative body” (Hogg, 1999:88) and NHS organisations came to rely on them to demonstrate that they had consulted the public through CHC representation. The CHCs did not all perform to the same standards (Hogg, 1999) and eventually, CHCs themselves came to be seen as part of the 'system' and concerns were raised regarding their effectiveness and independence. They were often under-resourced and excluded from the decision-making process (Lupton et al., 1995). The role of the CHC was not seen as a clear one and scepticism of their value prevailed from the 1980s and into the next decade (Seale, 1993). In 1982 the possibility of their abolition in *Patients First* (Department of Health and Social Security and Welsh Office, 1979) was rejected (Webster, 1998). As Webster (1998:161) claims of CHCs, "...although sometimes troublesome, they were not particularly influential".

*Working for Patients* (Department of Health, 1989) introduced the concept of the 'internal market' in the NHS: District Health Authorities (DHAs) 'purchasing' (later 'commissioning') care for patients from whichever 'provider' would deliver the most cost-effective service, bringing 'competition' into the NHS. Included in this plan were incentives for good performance and increase in productivity and patients were the 'consumers' in the market place, with a recommendation that the NHS use a business model for its operation. Applying a consumer model meant there was the “need to find out what the customers and consumers of Trusts are looking for” (Walton, 1997:49) and that this would ensure that the consumer voice was heard via market forces and applying marketing methods (Allsop, 1993).

National Health Service users, however, do not necessarily act like "conventional consumers" (Baggott, 1998:263) and patients were unable to choose which services they wished to 'consume' (Webster, 1998:202). Furthermore, the balance of knowledge, expertise and status favoured the health professions and was too "adversarial" (Baggott, 1998:263). Critics, therefore,

argued that the internal market “...produced the disadvantages of markets with none of the advantages” (Hutton, 2000:4) and consumerism was merely a response to public opinion that public services were not meeting the needs of “customers” (Ranade, 1997:162) .

*Working for Patients* (Department of Health, 1989) has also been accused of ‘weakening’ the power of CHCs by removing the right of members to attend meetings of the DHAs and placing a duty on members to negotiate a visit to inspect NHS premises – a task that did not always prove successful (Harrison, 1993:19; Hutton, 2000).

“Management led consumerism in the NHS received significant impetus” as a result of the *Griffiths Report* (Seale, 1993:69) and the subsequent White Paper. Salter (1998:18) argues that managers used patient power, demand and expectation as a lever to exert power over the traditional medical profession power base to limit their autonomy. However, although the *Griffith Report* referred to patient choice in General Practitioner (GP) and hospitals and GPs competing for patients by showing they could offer what patients wanted, there was no mention of actually asking patients what they wanted. Public opinion at this time saw the NHS as “ill-equipped to meet the legitimate expectations of its consumers” (Salter, 1998:5).

Along with CHCs, Non-Executive Directors (NEDs) were appointed to the Boards of NHS Trusts. They were regarded as representative of local people as they were drawn from the local community, for example, the Hospital League of Friends (Department of Health, 1989), though these ‘representatives’ were usually white, male business people (Harrison, 1993).

The *Patients’ Charter* (Department of Health, 1991), published by the Conservative Government, set out rights and standards the patient could expect within this consumer model: seven existing rights (including the right to be registered with a GP, to have access to their own health records and to receive

emergency medical care), three new rights (including detailed information on waiting times and complaints) and nine 'aimed-for' standards (such as, respect for patient privacy, limits on cancellation of operations and allocation of a named nurse) which went on to be revised and extended over the following few years. There have been suggestions, however, that the Charter served more to confuse the public because if the NHS organisation did not abide by those standards, there did not appear to be anything that the patient could do about it (Ranade, 1997; Harvey and Wylie, 1999).

*'Local Voices'* (NHS Management Executive, 1992:1) expanded on the *Patient's Charter* calling for a "radically different approach" to the on-going patient involvement of health authorities in purchasing of healthcare, focusing on listening, informing, discussing and reporting. There was recognition that patient expectation would need to be managed as not everything patients would want could be delivered and that health authorities should work with other agencies as patient 'wants' may go beyond health authorities direct control. The document declared that it was important to get the views of the "silent voices" (vulnerable patients and those not part of a wider patient or community group), suggested techniques for involvement and proposed a proactive approach to stimulate discussion rather than await reaction (NHS Management Executive, 1992:8).

Seale (1993) claimed that the NHS was still very paternalistic and bureaucratic and favoured the medical professions rather than be responsive to the needs and wishes of patients. Voluntary organisations and community groups were often not given enough time to consider consultation documents and there was a perception that this was just a 'tick the box' process; the decisions had already been made (Harvey and Wylie, 1999; Gulland, 2003).

Rowe and Shepherd (2002) argued that while the 'new public management' (NPM) approach (Flynn, 2001) to the health service prevailed, public influence over decisions would remain at the discretion of management. The new

policies for consultation did not take the principles of patient participation to the next level of involvement at the planning and decision-making stage and there needed to be a "move away from one-off consultation" (NHS Management Executive, 1992:1). From the mid 1990s, local NHS bodies and trusts "experimented" with patient involvement exercises, but this was seen by some as health authorities making a move to destabilise CHCs and minimise their influence .(Hutton, 2000:35).

Around this time, commentators suggested that public involvement was causing "overload" – of staff, decision-makers, data and public involvement regulators. Public Involvement activities produce vast amounts of qualitative and anecdotal information which, they argued, could seem a daunting task for decision-makers who need to know "the bottom line" (Roberts and Marshall, 1999:6).

Successful public involvement was seen as being constrained by bureaucracy with a lack of infrastructure at a local level and no specific person or department with responsibility for PPI (NHS Executive, 1996). The *'Patient Partnership'* strategy (NHS Executive, 1996) set out four overall aims with a keynote of partnership at both an individual level and collectively: to promote and increase user involvement; to ensure services are more responsive to the needs of patients; to enable patients to make informed choice and; to provide service users with the knowledge and support to influence decision-making. Despite the rhetoric, Harrison et al., (2002) claimed that public involvement had actually decreased between 1948 and 1997.

However, even the change in Government in 1997 could not stem the tide of the new ethos of consumer involvement and the New Labour Government "conspicuously rededicated itself" (Webster, 1998:217) to the principles of involving the public, at least in terms of rhetoric and policy, as will be shown in the next section.

### 2.2.3 Public Involvement

The White Paper '*The New NHS: Modern, Dependable*' (Department of Health, 1997) highlighted rebuilding public confidence in the NHS as one of the key principles encompassing being influenced by patient views, increased openness (such as holding Trust Board meetings in public) and driving quality through including the patient's experience. The document emphasised that the new Primary Care Groups (PCGs) and later, Primary Care Trusts (PCTs), must have effective arrangements for public involvement. In the analysis of this document, critics declared that after 18 years of Conservative Government, the NHS was in debt and staff morale was low, as was public confidence in the NHS (Baker, 1998). Baker argued that only financial investment could rectify this and that public involvement alone was unlikely to have the required outcome of increasing public confidence. McIver (1998) talked of the confusion and uncertainty as to the extent of public involvement required, that the NHS was still unclear how to relate to the CHCs and cited a lack of statutory changes to address this issue.

The NHS Executive (1998) explained the establishment of PCTs and their function, subject to the health bill being successful, as being separate statutory bodies with their own budget for local healthcare and the ability to commission health services. They cited PCTs as being in a position to listen to patients, calling for embedded public involvement and accountability to the public through lay members on the Board, Board meetings held in public, complaints procedure and relationships with the CHC (Farrar, 1999).

At the same time, it was recognised that health care professionals can feel threatened by the concept of public involvement, this in part being due to their professional training and background. "Professionals have been trained to practice in a particular way on the basis of professional knowledge" and their expertise is based on that training (NHS Executive et al., 1998:5). It was suggested that at a national level this should be addressed through professional

organisations and Royal Colleges to promote the understanding and a commitment towards public involvement.

The Department of Health (1999a:i) admitted that for NHS staff "working in partnership with patients, carers and the public ...will represent a major change to their traditional ways of working" and questions continued to arise regarding the influence or impact on decision-making (McIver, 1999).

*'Patient and Public Involvement in the new NHS'* (Department of Health, 1999a) built on the aims of the *Patient Partnership Strategy* (NHS Executive, 1996) announcing that patient partnership should be fundamental to the work of all NHS bodies, effectively making PPI mainstream. PCTs were encouraged to identify a named individual in a senior position who would take responsibility for PPI strategy and ensuring its implementation (Department of Health, 1999a), preferably a 'champion' of PPI on the Board who supports, promotes and enables the work of PPI from that level. National Service Frameworks (NSFs) would set standards for clinical care that would contain elements of public involvement and each Trust would be expected to carry out the new National Patient Survey locally to determine patient satisfaction. Clinical Governance frameworks were to include monitoring the patient experience and responding to ensure that PPI was "integral" to service planning and delivery within the new PCGs (Department of Health, 1999a:11). However, Rea and Rea (2002) criticised the strategies for being backward-looking and not offering enough support for managers and professionals looking to change their services and improve performance.

PCGs were tasked with ensuring (a) that PPI strategies and policies were developed, (b) they had a robust means of demonstrating how they had gleaned the public views, (c) partnership working with local CHCs were in place and (d) "resources" to support lay representatives were available (Department of Health, 1999a:12) - it was considered "unreasonable" to expect members of the

public to fund their involvement in NHS decision-making (Department of Health, 1999a:17).

The paper highlighted a framework for monitoring progress on PPI, which included keeping a record of PPI activity, developing a strategy, training and education of staff to carry out PPI, a commitment to PPI from the highest levels of Trusts, working with other agencies towards common goals of obtaining public views and a process of evaluation. It was made clear that PPI should not be just one person's job (Department of Health, 1999a). To demonstrate their commitment to PPI, the Department of Health went on to inform that the Commission for Health Improvement (CHI) would review clinical services in Trusts and monitor them to ensure effective PPI had taken place. They also stated that they had commissioned a £2.5 million research project, '*Health in Partnership*', to study how best to involve the public at all levels of decision-making in the NHS. The results of the *Health in Partnership* (Farrell, 2004) project were published in 2004 as evidence for policy implementation (see later in chapter).

In 1999, the Association of Community Health Councils of England and Wales (ACHCEW) set up 'The Commission on the NHS' to independently examine how the NHS was meeting its accountability to the public (Hutton, 2000:2). The subsequent report claimed that "a gap has opened up... between what the NHS is able to deliver and the expectations and the needs of the user" (ibid 2000:2) and that from their own research, 20% of people felt they had no power over the treatment they received. This feedback was used as an argument that people were still not being consulted and involved.

At the end of the millennium, it was perceived that public involvement still had some way to go before reaching maturity (Chambers, 1999), CHCs saw themselves as the public relations arm of health authorities, merely responsible for communicating and enabling their work (Hutton, 2000:59). "Involving the public implicitly recognises that medical expertise cannot provide all the



answers in all situations” and a change in attitude would be needed (Jakubowska and Crossley, 1999:2) while some NHS managers and clinicians perceived PPI as “indulging in a fashionable whim” (Chambers, 1999:2).

#### **2.2.4 The new millennium**

*Patients are the most important people in the health service. It doesn't always appear that way. Too many patients feel talked at, rather than listened to. This has to change... Patients must have more influence over the way the NHS works. (Department of Health, 2000:10.1)*

The *NHS Plan* (Department of Health, 2000:1.3) stipulated that the NHS was to be remodelled to be patient focused over the next ten years and first announced their intention to replace CHCs. Chapter 10 of the *NHS Plan* outlined some of the key elements of public and patient involvement that PCTs must apply to become “commonplace” by 2010. This included the Expert Patient Programme, a self-management course for people with long-term conditions; patient choice on treatment, both in terms of practitioner and place; a Patient Advocacy and Liaison Service (PALS) to inform and support patients and carers through their dealings with the NHS; Patient’s Forums and scrutiny of the NHS. The Government purported to want to move away from a system of patients being on the outside, to one where the voices of patients, their carers and the public generally are heard and listened to through every level of the service, acting as a lever for change and improvement.

The *NHS Plan* gave its commitment to “modernise, deepen and broaden” the influence of patient views from the old CHC system (Department of Health, 2000:10.23). Every Trust would be required to produce a Patient Prospectus, not just to publicise the services available, but to include how NHS organisations had listened and responded to the views of patients and carers, including via a new national patient survey.

Patient Forums were to be established in every NHS Trust and Primary Care Trust, half elected from local patient and voluntary organisations, the other from respondents to the patient surveys. PALS staff would support the Forums. The scrutiny role of the CHC would now be undertaken by elected local Government councillors.

To demonstrate the Department of Health's commitment, *the NHS Plan* pledged to increase PPI in the various professional regulatory bodies, for example the NHS Modernisation Board and the National Institute for Clinical Excellence (NICE).

The *Bristol Royal Infirmary Inquiry* was set up in 1998 to investigate the deaths of 29 babies undergoing heart surgery at the Bristol Royal Infirmary between 1984 and 1995. The *Final Report* published in 2001 (Bristol Royal Infirmary Inquiry) also provided recommendations for wider reforms of the NHS. Of the almost 200 recommendations, ten were concerned with PPI through empowerment of patients and carers and nine of those had a direct implication for PCTs. Some had already been pre-empted in the *NHS Plan*: embedding PPI; scrutiny; PPI in development and planning; wider PPI, not just patient groups; evaluation and; financial resources.

The national survey programme was implemented in 2001 to obtain feedback from patients about their experiences of health care and provide views that would help determine the star ratings of Trusts (Department of Health, 2003c).

Whilst the Department of Health was still forming its response to the *Bristol Inquiry*, the *Health and Social Care Act 2001* (Parliament) was passed, placing a statutory duty on NHS Trusts, PCTs and Strategic Health Authorities (SHAs) to make arrangements to consult members of the public as an on-going process not just during times of change. Section 11 (Parliament, 2001:15.1.11) states:

*It is the duty of every body to which this section applies to make arrangements with a view to securing, as respects health services for which it is responsible, that persons to whom those services are being or may be provided are, directly or through representatives, involved in and consulted on:*

- (a) the planning of the provision of those services,*
- (b) the development and consideration of proposals for changes in the way those services are provided, and*
- (c) decisions to be made by that body affecting the operation of those services.*

Section 7 of the Act (Parliament, 2001:15.1.7) detailed the function of the new Overview and Scrutiny Committees (OSCs), giving them the right to review and scrutinise the health service.

In September of the same year as the above Act, the Department of Health published a 'Discussion Document' around *Involving Patients and the Public in Healthcare* (Department of Health, 2001a) asking for public comment on how patients and the public should be involved in influencing the NHS and the structures with which they proposed to replace CHCs and ACHCEW.

The proposals included a statutory new body, 'Local Voice,' per SHA, working with Local Strategic Partnerships and co-ordinating the work of Patient Forums with an over-arching national body, 'Voice – the Commission for Patient and Public Involvement in Health' (VCPPIH), to oversee standards and quality of Forums, provide training and to support the voluntary sector in having a voice. In November 2001, the response to the discussion document was published (Department of Health, 2001b) highlighting seven themes for incorporation which included the need to have clear lines of accountability, simplicity of structure and consistency across the country. There was also a pledge to produce guidance for PPI by April 2002 and six criteria for successful PPI were identified. It needed to be effective, accessible, accountable, integrated, independent and adaptable.

*The NHS Reform and Health Care Professions Bill* (Department of Health, 2001c) became an Act of Parliament (Parliament, 2002b), was passed on the 13<sup>th</sup> June 2002 and became a legal requirement in January 2003. It included the future abolition of CHCs and ACHCEW, the establishment of Patient Forums, that “must obtain the views of patients and carers” about Trust services (Parliament, 2002b:17.1.15.3b) and the founding of the renamed Commission for Patient and Public Involvement in Health (CPPIH) – to be known as The Commission. The abolition of CHCs was seen as a controversial element of the Bill (Gould, 2001; Wright, 2001; Shannon, 2004; Baggott, 2007); although inconsistent, CHCs had been seen as authentic advocates for patients (Gould, 2001). As discussed earlier, many saw CHCs as obsolete, unchanged and not delivering what they were set up to do (Eames, 2002), with patchy performance (Stephens, 2001). Others believed the CHCs were abolished as they were too effective (Rathfelder, 2005) and part of a bigger political agenda (Palmer, 2004).

Public opinion was that the new patient and public involvement forums were a reinvention of the old CHCs, but not as strong or effective (Socialist Health Association, 2002). Sang (2002:1), a leading commentator in the field of public involvement, claimed that the NHS now risked "tokenism on a grand scale" if the current "traditional paternalist-consumerist" model of involvement did not shift to the new paradigm of a "pluralist" model.

In the meantime, the Government's response to the *Bristol Royal Infirmary Inquiry* (Department of Health, 2002c) agreed with all the recommendations around public involvement through empowerment and accepted that the current structure was an “outdated model”. The public "should be on the 'inside' rather than represented by some body on the 'outside'" (Department of Health, 2002c:123). It gave a reminder of all the policies that had been put in place in the meantime, such as the recent *Health and Social Care Act* which had “enshrined in law” the NHS duty to involve the public (Department of Health, 2002c:123). It also mentioned the *NHS Reform and Health Care Professions*

*Bill* (Department of Health, 2001c) plans for Patient Forums and CPPIH to “build capacity within communities for... involvement” (Department of Health, 2002c:124) with a “team of specialists for each Strategic Health Authority Area” (Department of Health, 2002c:129).

PPI began to be built into targets and priorities for NHS organisations and the *‘Priorities and Planning Framework for 2003 – 2006’* (Department of Health, 2002b) stated that PCTs should involve patients and the public in putting in place local plans. *‘Delivering the NHS Plan’* put “patients in the driving seat” of the NHS (Department of Health, 2002a:24), giving them a choice of appointments “at a time and place convenient for the patient” (Department of Health, 2002a:23). By 2004, PCTs were expected to hold 75% of the NHS budget, in the belief that power held locally would enable local services to respond to the needs of patients and PCTs were expected to produce a prospectus which included PPI feedback. The document talked of establishing a single body for regulation and monitoring of the NHS; the Commission for Healthcare Audit and Inspection (CHAI), replacing CHI, and being responsible for the performance ratings (the so called ‘star ratings’) of all NHS organisations.

The promised *‘Health in Partnership’* research (Harrison et al., 2002; Farrell, 2004), though not published until 2004, had completed most of its fieldwork by the end of 2001. This is of importance to note for the context of the findings, as many of the Primary Care Groups/Trusts had not had time to become established organisations, having been in existence less than a year. Plus, the Health and Social Care Act (Parliament, 2001) making public involvement a statutory duty for NHS organisations, had not yet been developed. Of the 12 pieces of research giving evidence for PPI policy implementation, six focused on collective public involvement and PPI training and education issues. The research reinforced the benefits of public involvement, but found that beliefs, attitudes, behaviour, time, communication and leadership all needed to improve if PPI was to be successful and was cited as “one of the greatest challenges”

facing the NHS (Farrell, 2004:29). Leadership and commitment at Board level was seen as vital for long-term cultural change (Anderson et al., 2002; National Consumer Council (NCC), 2002a), but Farrell (2004) argued that this was no guarantee that change would happen. She argued that attitudes and behaviour could make or break the PPI process and yet there was “little evidence that opportunities to explore values and beliefs was taking place” (Farrell, 2004:31).

Commentators (Jakubowska and Crossley, 1999) maintained that staff found implementing public involvement rewarding, but that training and practical experience was fundamental if the new change in culture was to be achieved.

A month after the *Health and Social Care Act* made PPI a legal requirement and nearly a year later than planned, the Department of Health published its guidance for PPI (with input from me) in February 2003. Entitled ‘*Strengthening Accountability*’, it comprised of two parts; Policy Guidance (Department of Health, 2003d) and Practice Guidance (Department of Health, 2003e), the former indicating the duties and responsibilities of PPI for Trusts, the latter providing examples of how to realise those duties. Much of it echoed the ethos and recommendations of ‘*Local Voices*’ from 1992 (NHS Management Executive). Chapter 12 of the Practice Guidance explained in more detail the five elements of the new system of patient and public involvement which had broadened duties formerly the remit of CHCs:

- I. The Commission for Patient and Public Involvement in Health (CPPIH) – an independent, national statutory body set up in Birmingham in January 2003 responsible for submitting reports to, and advising the Government on, how the PPI system is functioning (Butler, 2003) .
- II. Patient and Public Involvement Forums (PPIFs) - 572 PPIFs, one for each NHS Trust in England, tasked with working with all sectors of the community and finding out what people really think about health in their local areas (Butler, 2003) .

- III. Overview and Scrutiny Committees (OSC) - to review and scrutinise any matter relating to the planning, provision and operation of health services in the area of its local authority, with a particular emphasis on ensuring there has been public consultation (Parliament, 2002a).
- IV. Independent Complaints Advocacy Service (ICAS) – eleven ICAS providers offering independent advocacy and support to people in England wishing to complain about the care or treatment they have received under the NHS (Department of Health, 2004b).
- V. Patient Advice and Liaison Service (PALS) – no longer ‘advocacy’, a service available from every NHS Trust to provide information and support patients on their ‘pathway of care’ through the NHS. They were to “monitor problems and proactively seek patients’ experience of health care, including problems arising, and highlight gaps in services” (Department of Health, 2004h).

Only in the introduction did it draw attention to the need to set all the PPI activity into a programme of change management, if the outputs were to produce outcomes in terms of changes in healthcare.

When the NHS Modernisation Board (2003:i), published their progress on the implementation of the *NHS Plan*, the key emphasis was the need for a change in the culture of the NHS to succeed in (a) modernisation and (b) ensuring that it meets the public’s “right to expect that services they have agreed to fund will meet their aspirations”. 90% of all patient treatments took place in primary care in 2002, and yet the NHS was still not listening to the voice of patients. It cited several ways of thinking that would be needed on top of financial investment to bring about the enormous cultural change with staff questioning the way they deliver services, leaders with vision to lead change and staff morale playing a key role in this process, increased communications skills and a focus on public involvement in pre-registration programmes and higher staff morale. At the same time, it maintained that staff were no longer experiencing the same levels of “change fatigue”.

Continuing the theme of progress, the House of Commons Health Committee carried out an investigation into how far the new process of public involvement had been implemented, in particular the transition from the CHC system (House of Commons Health Committee, 2003). The conclusion drawn was that there was little information available to establish how successful the implementation had been to date and yet £69 million was spent on patient and public involvement in 2003 (House of Commons Health Committee, 2004.5.1). Serious doubts were cast about the functioning of the PALS service across the country, it was declared that staff and the public were confused and uncertain about the new structures and it urged the Government to delay the abolition of CHCs until the new Patient and Public Involvement Forums were in place. Watts (2003:326) pointed out that the challenge for CPPIH was to replace CHCs when the public was “mourning their passing” and only 28% wanted to have more say in what the Health Service is doing (Jennings et al., 2003).

Researchers also found that despite a clear commitment to PPI, few Primary Care Groups had an implemented PPI strategy and that it was mainly the involvement of other organisations in PPI activity which led to much of the success that had been achieved, perhaps due to their additional resources and skills (Bond et al., 2003). Most Chief Executives agreed that PPI was difficult and cited holding Board meetings held in public as their key way of involving the public. Main barriers for involving the public were getting the public interested, competing PCG commitments (Anderson et al., 2002), finding the appropriate groups to engage and lack of skill. A theme of learning by experience and mistakes emerged with little attempt to learn from good practice elsewhere. Recommendations included multi-agency working (an argument supported by others (NHS Wales, 2001; Anderson et al., 2002)), national guidance on PPI training and ensuring there are identified resources to enable the work.



The Picker Institute Europe, one of the key bodies working on behalf of patients, argued that “many people now approach their healthcare in the way they would buying a new car” (Coulter, 2003:18) and in August 2003, the Department of Health (2003b) began its national consultation to find out what choices people would want to make about their health and health services. Over 110,000 took part in the Choice consultation (Wyatt, 2004). *Building on the Best* (Department of Health, 2003a) was the Government response to the findings and gave priority to giving people a bigger say in their own healthcare decision-making and how they would be treated and a choice of appointments at a time and place and with services to suit the patient. The Government declared that the rhetoric of patient choice needed to be supported by a commitment to fund and resource the initiative (Department of Health, 2003a).

The *NHS Improvement Plan* (Department of Health, 2004d:77) stated that the new Public Service Agreement (PSA) had four broad themes, one of which was the patient, carer and user experience to ensure that “service provision is more consumer focused.” PPI was declared a ‘core standard’ expected from healthcare organisations that was “not optional” and “should be met from date of publication” of the document in July 2004 (Department of Health, 2004c:27). PCTs were now to demonstrate that they had consistently involved the public and listened to the views and needs of the local population when drawing up their Local Delivery Plans (LDPs) for health care.

### **2.2.5 A ‘brick wall’**

Despite the plethora of policies, targets, priorities and progress reports, it was recognised that creating meaningful public involvement was not easy (NHS Executive, 1996; Crawford et al., 2002; Bond et al., 2003). This was a view which appeared to be reflected in the findings of a Commission for Health Improvement (CHI) (2004) report which found that from more than 300 inspections of NHS organisations and from its own research into the topic, there

were no examples of excellence in involving patients at any of the Acute or Primary Care Trusts inspected to date. They went on to say:

*The NHS is, on the whole, improving in some aspects of PPI, such as providing information for patients and undertaking qualitative and quantitative exercises in getting feedback from patients. But it is not doing as much to ensure that patients, carers, service users and the public influence decision making...*

*...Organisations are failing to integrate PPI activities with other efforts to improve services and are not making PPI central to core activities...*

*...Involvement is not leading to improvement...PPI is not yet having a major impact on policy and practice. It is almost as if there is a brick wall between the activities going on and any changes on the ground that happen as a result.*

(Commission for Health Improvement (CHI), 2004:11)

CHI argued that “organisations are running before they can walk” (2004:2), that though there are members of staff with knowledge and experience in public involvement they are “too often isolated and overwhelmed by the agenda” and recommended that a PPI coordinator needed to be a “change agent” (2004:3). CHI went on to state that PPI has been successful where staff concerns have been tackled but that, so far, organisations had failed to embed PPI into the “corporate bloodstream” (2004:12). “Patients soon become cynical about organisations that claim to ‘listen’ without them taking action” (Patients Association, 2004:3).

It was pointed out that public involvement should not be seen as a “chore” (Audit Commission, 2002:3) and that any activity which is embarked upon without the ‘hearts and minds’ of staff and agencies involved is unlikely to succeed. If Trusts carried out PPI merely because they were directed to, it would not be successful (Audit Commission, 2002). Numerous critics argued that much depended on a change in culture and attitude within the NHS

nationally and locally (Jakubowska and Crossley, 1999; Audit Commission, 2002; King's Fund, 2002; Farrell, 2004; Rose et al., 2004; Sang, 2004b).

Gillespie et al., (2004:146) found that from a service user's perspective, there was still "evidence of professionals' reluctance to change" and a "divergence of views between clinicians and managers". They, too, criticised the Government for placing too much emphasis on the organisational side of public involvement rather than the individual.

*'Getting over the wall'* was the Department of Health's (2004a) response to CHI's criticism. It focused on 21 practical examples and case studies highlighting where PPI had led to service improvement around the country, from learning difficulties, chronic conditions and maternity services to mental health, paediatrics, older peoples services and sexual health services. It declared that "outputs" of public involvement were not influencing "outcomes" and asked how many NHS organisations were "guilty" of not being able to work past the policy and process stage of public involvement, making it a mere tick-box exercise (Department of Health, 2004a:9). This was a claim that had been made before (National Consumer Council (NCC), 2002a; Anya, 2004; Department of Health, 2004a). It stressed that PPI was everyone's responsibility.

The new national PPI structures and policies received criticism, too, proclaimed as "piecemeal and disparate," unlikely to increase public accountability if democratic accountability remained with the Secretary of State and that without change it would cost "time, effort and resources without conferring any significant benefit" (Florin and Dixon, 2004:161). Walker (2005) argued that most PPIFs across the country were so far a "joke" and the Forum members themselves admitted to feeling disempowered (Rathfelder, 2005).

The complexity and time required for staff to carry out public involvement had "come as a surprise" and lead to stress and overload (Roberts and Marshall,

1999:5). Lack of time and money was cited as a barrier to implementing public involvement (Anderson and Florin, 2000; Cole, 2001) and “in the rush to obtain public input” staff lacked information and felt left out of the process (Roberts and Marshall, 1995:5).

Rutter et al., (2004), found that some staff expressed reservations and even “resentment” towards the polices for public involvement, worried that patients would be volatile due to their condition and were unable to fully consider a role for patients in decision-making. Staff were often not aware of the public involvement polices within their own organisations, were unsure how to go about listening to patients and held a belief that directives for service delivery were coming from the Governments, so there was no scope for local decision-making anyway. Nurses felt that they themselves were not able to influence policy, let alone a patient having such power and they expressed concerns that they would bear the brunt of user criticism. They concluded that the balance of power around decision-making remained firmly with the provider organisation, which concentrated on the process of involvement. This case study took place in a mental health setting, where user involvement has traditionally had longer to take root. However, the findings support many other studies which indicate user involvement does not lead to change unless that change was already supported by the organisation.

Roberts (1995:21) argued that PPI was “not a fad” and that the progress of technology, communications and the demand for the public to be involved in influencing decisions that affect them was not going to go away. Commentators suggest that a “new paradigm” was emerging that integrated the ideals of “consumerism and citizenship” and challenged all stakeholders from the patients and public to the professionals and public authorities to rethink their roles, relationships and responsibilities (Sang, 2004a:187).

CPPIH had been established just over a year when the Department of Health announced its plans to abolish the ‘arm’s length body’ (Department of Health,

2004f). This announcement was met with condemnation from a raft of patient and consumer groups (Batty, 2004; Hebert, 2004; Department of Health, 2005b) and concern that lessons had not been learned from the abolition of CHCs. Grant (2004) described the days ahead as crucial. The King's Fund and the Consumer's Association (in Shannon, 2004) voiced their concerns, questioning what would take its place to ensure there are effective frameworks in place to integrate patient and public involvement. The Department of Health (2005b) carried out a large programme of public consultation on the future for PPIFs when CPPIH was abolished, with nearly 5,000 people proffering their views. There was widespread disillusion with CPPIH from PPIF members and with many of the Forum Support Organisations which supported the PPIFs, citing disorganisation, lack of leadership, both at a local and national level, lack of training, information and direction, and an acknowledgement that PPIFs were not in touch nor representative of their local populations.

Harry Cayton, Director for Patients and the Public at the Department of Health, argued that the UK is "pioneering the way" in incorporating the public's needs and wants into a public body organisation (Wyatt, 2004). He described five key requirements for public involvement:

1. *going to people instead of expecting them to come to you;*
2. *listening to what they have to tell you;*
3. *discussing their views with them;*
4. *acting on them and;*
5. *feeding back to people what has been done as a result of their involvement* (Wyatt, 2004).

Others supported the idea that PCTs should take the approach of "listen, consider, respond" but suggested that there was little evidence that public involvement was having a direct influence on change (NHS Alliance, 2004b) and others argued that increased opportunity for public involvement provided no indication that this would have on influencing decision-making, that the methods of involvement were open to challenge in terms of their validity and

that there was no evidence to suggest that patients actually wanted these mechanisms of involvement promoted by the Government (Milewa, 2004).

One of the six consultation criteria for written consultations included the requirement for the department carrying out the consultation to evaluate the effectiveness of the process which they say should be via a “designated consultation co-ordinator” within each department (Regulatory Impact Unit, 2004:4), though there was no legal requirement for public bodies to follow this code.

A competency framework was published for PCTs to establish if they were meeting the required standards (Engaging Communities Learning Network, 2005). Part 7 was around PPI and included:

1. Strengthening accountability (communication, Board meetings in public, working with OSCs, corporate governance, Local Delivery Plans and the Expert Patient Programme).
2. Local Compact (between public and community/voluntary sector).
3. Patient experience (range of methods for involving the public, national surveys, PALS).
4. Staff involvement with the public (culture of involvement, day-to-day PPI, trained and skilled staff).
5. Policy implementation (learning from good practice, PPI in staff appraisals, embedded in organisation).
6. Scrutiny and review (working with PPIFs, CPPIH, CHAI etc).

*‘Standards for better health’* (Department of Health, 2004g:15) set core standards for health services that PCTs had to demonstrate they had met, including “the views of patients, their carers and others are sought and taken into account in designing, planning, delivering and improving healthcare services”. This move was welcomed by PPI commentators:

*“Demonstrating to the Healthcare Commission and, more importantly, to local people themselves, that the PCT possesses the capability and openness to initiate and facilitate engagement, will be vital to success” (Sang and Keep, 2005:6).*

## **2.2.6 Creating a ‘patient-led’ NHS**

‘*Creating a Patient-led NHS*’ (Department of Health, 2005c) highlighted how Patient and Public Involvement had evolved over the years, strategies and toolkits were in place and PPI was expected to take place in the NHS as part of its every day work and should lead to improvement in terms of the patient experience, with an emphasis on managing change. In 2006, Parliament consolidated the Health and Social Care Act of 2001 into the new NHS Act (Parliament, 2006), but made no substantial changes to the law and none to the arrangement for patient and public involvement. The White Paper ‘*Our health, our care, our say*’ (Department of Health, 2006c: 157:161) talked about PPI in the commissioning process and “more rigorous fulfilment of existing duties to involve and consult”, measuring the success of that duty – and the responsiveness of the organisation - through new performance targets. The consultation around the White Paper itself received criticism for the cost (estimated at over £1million) (Lloyd, 2005). Later that year, the new National Centre for Involvement, a consortium of the University of Warwick, the Centre for Public Scrutiny (CfPS) and National Voices (formerly Long Term Conditions Alliance), was launched to support organisations with their PPI duties by providing a knowledge and resource base for the NHS (The NHS Centre for Involvement, 2006). Reports of PPI that had little or no impact on decision-making continued (Coulter, 2006) and criticism of section 11 PPI legislation whereby NHS organisations attempt to avoid consultation or carry out consultation that merely “rubber stamps” a decision already made (House of Commons Health Committee, 2007b).

The Government's *'Together we can'* programme recognised the increasing desire for accountability and democracy linking policy and local decision-making and the need to stimulate participation (Community Empowerment Division, 2006). They stressed the need to ensure individuals and community groups are heard and responded to (Department for Communities and Local Government, 2006), linking all public sector services in this 'duty'. Following a period of consultation (Department of Health, 2006d) the Department of Health produced their proposals to create 152 new health and social care Local Involvement Networks (LINKs) to replace PPIFs (Department of Health Patient and Public Involvement Team, 2006), with plans for one LINK within each area of local authority that had responsibility for social care. The new LINKs would use networks of engagement and relationship-building with local people and community groups to monitor services and ensure that the commissioning of services is influenced by the views of local people. The paper talked of PCTs being able to utilise LINKs to reach local people and that commissioners would find the PPI research carried out by LINKs invaluable in decision-making. Criticism of abolishing PPIFs so soon after they were created and bringing in a new system focussed on lessons not being learned from history, particularly the mistakes and successes of Community Health Councils (Hogg, 2007) and that a further reorganisation would cause confusion and cynicism (Warwick, 2006; Dyer, 2007; House of Commons Health Committee, 2007b; White, 2008).

The reform programme to develop first class commissioning (Department of Health, 2006b) highlights the use of "extensive" PPI by commissioners to improve the health of the population and reduce inequalities. It cites the voice of patients through choice as a driver for service improvement by healthcare providers, with communities able to petition for improved performance. Systematic reviewing of current services and contract to ensure high performance and quality standards, in addition to robust commissioning of new services and a significant role for practice based commissioners are outlined.



In 2007, the Local Government and Public Involvement in Health Act (Parliament) legislated on the proposals to abolish PPIFs and created LINKs from March 2008, and imposed a duty on NHS services providers (including PCTs) and local authorities to respond to requests for information and recommendations. It also amended S242(1B) of the NHS Act 2006 by stating that “users... whether directly or through representatives, are involved (whether by being consulted or provided with information, or in other ways)” in planning and decision-making that would have an impact on the way services are delivered or the range of services available . The pertinent changes in wording are highlighted in bold in the Table 2.3:

<b>Section 11 of the Health and Social Care Act 2001</b>	<b>Section 242(1B) of the NHS Act 2006</b>
<p><i>It is the duty of every body to which this section applies to make arrangements with a view to securing, as respects health services for which it is responsible, that <b>persons to whom those services are being or may be provided</b> are, directly or through representatives, <b>involved in and consulted on:</b></i></p>	<p><i>Each relevant English body must make arrangements, as respects health services for which it is responsible, which secure that the <b>users of those services, whether directly or through representatives, are involved (whether by being consulted or provided with information, or in other ways)</b> in –</i></p>

**Table 2.3: PPI legislation changes**

Section 11 obliged NHS organisations to consult future users of services in any changes, whereas S242(1B) specifies current users of services. Although at (1F) it clarifies that the term ‘user’ should also refer to potential users, this is lost in the guidance to which most organisations refer, rather than the Act itself. A small but significant change in that PCTs could chose not to consult the wider public on a service change, only those using services. In addition, it appeared to provide qualification for the term ‘involved’ giving NHS organisations permission to only provide information as a method of

involvement, potentially diluting the previous message of having moved away from passive recipients of healthcare change (Vincent-Jones et al., 2009).

The NHS Choices website was launched in June 2007 to provide information about health services to help patients make choices about their healthcare. In the summer of 2008 it expanded to allow patients and the public to compare performance and experience about healthcare services, providing an opportunity for the local population to express their views publically and directly (Department of Health, 2007a). The site has been criticised directly via patient comments for lack of response to the patient feedback and for using such a patient comment system for obtaining patient views, particularly when partnering with an independent public opinion research company might have been deemed by organisations a more credible source of public views to which a response could be given (Carlisle, 2008; Health Direct official NHS blog, 2009).

The legislation into practice guidance for PPI was published in 2008 (DH Commissioning and System Management - PPE, 2008) (with my input) emphasising the requirement for PPI to inform decision-making and for NHS organisations to be able to demonstrate how PPI activity has made a difference to a planning outcome. The guidance sought to remove the ambiguity of the future patients versus current services users in the revised legislation by defining a ‘user’ as someone who may use services and people who are or could be affected by any proposals for change. It also described the need to use a range of PPI methods at different points of the commissioning cycle, which may at times mean providing information. It provides an illustration of an ‘involvement continuum’ showing giving information as a ‘technique’, however, this is at conflict with the guidance which clearly requires PCTs to be able to actively demonstrate how patient views have influenced decision-making, which means that providing information cannot be a method of obtaining views, but more a technique to be used in addition to more two-way engagement. PCTs, as commissioners, are required to produce annual reports

of PPI activity, demonstrating how that activity has influenced decision-making and flagging future PPI projects for the year ahead. Further guidance was to be produced detailing the format and content of such a report (which I subsequently helped to write).

According to the guidance, patient and public views are defined as equally weighted with any change being affordable and clinically safe and effective. The national review of the NHS (Darzi, 2007) emphasised that no change to services should happen without evidence of clinical need, and although advocating the early involvement of the public and clearly defined outcomes for patients, clinical leadership is the basis for decision-making.

In the meantime, the Health Select Committee found that PPI continued to be “ineffective”, that there was wide variance in how Section 11 of the Health and Social Care Act was implemented nationally and that PPI Forums were not getting value for money (House of Commons Health Committee, 2007a). The Picker Institute (Chisolm et al., 2007) carried out a survey of PCTs to determine how prepared they were to engage patients and the public in healthcare commissioning, but while asking how frequently they met with patient forums and their perception of the influence they have in commissioning decisions, the focus was on the PPI activity itself and the finances and structures to support it.

At the end of 2007, the Government’s vision for World Class Commissioning was launched (Department of Health, 2007c:7-15) with a requirement for commissioners (PCTs) to have a “good understanding of what really matters to patients, public and staff”, where commissioning decisions “reflect the needs, priorities and aspirations of the local population”. 11 core competencies were detailed (Department of Health, 2007b) with competency three – ‘engage with public and patients’ – explaining the skills required to be competent, such as feedback evaluation, survey management and influencing skills, and the process and knowledge requirements, for example ensuring patients know how they can influence decision, and example outputs, such as evidence of engagement with

patient groups and communities. The accompanying assurance handbook (Department of Health, 2008a:77) described how PCTs would be assessed against the competencies, with four levels of achievement, where level 4 is considered world class. Key elements for PPI are as follows:

- *“The PCT demonstrates that they know the impact of their involvement and engagement and know how effective it is through evaluation that demonstrates improvements in people’s health and experience of services.*
- *The PCT has successfully deployed innovative approaches to engagement*
  - *Which have been shared with other PCTs*
  - *Which have led to high levels of engagement with hard-to-reach groups*
  - *Which accessed non-traditional partners e.g., criminal justice system.*
- *The PCT can demonstrate how proactive engagement and partnership arrangements with the local community, including LINKs, is embedded in all commissioning processes and drives decision making.*
- *The local population strongly agree that the local NHS listens to the views of local people and acts in their interest.”*

In a study between January 2008 and January 2009, the Healthcare Commission (Healthcare Commission, 2009) found that few trusts could provide evidence that the influence of PPI outputs was embedded in the day-to-day decision-making process and that patients and the public still felt that trusts do not genuinely wish to engage with them. Overall, they determined that PPI was rarely the impetus for changes or improvements in healthcare. When they indentify the characteristics for effective PPI, however, they provide more emphasis on the engagement activity and less on how to ensure PPI influences decision-making. The National Centre for Involvement proposed a systematic review to close the gap in PPI being regarded as important for democracy as

opposed to a vital component for making evidence-based decisions on healthcare (Staniszewska et al., 2008). Whilst the NHS Confederation highlighted demonstrating how patient views had shaped decision-making as a principle for accountability (NHS Confederation, 2008).

The Picker Institute survey of PCTs in 2009 (Picker Institute Europe), following on from their previous work in 2007, explored the early impact of world class commissioning in terms of PPI within a PCT. An overall shift in accountability from a PPI 'lead' to a more senior position and the Chief Executive was shown, with most participants seeing potential for the outputs of PPI to have greater influence on commissioning decisions. Once again, concern is raised about how the views of patients and the public influence decision-making when weighted against competing demands of targets and performance. They summarise that WCC has "boosted information gathering – but not decision-making" (Picker Institute Europe, 2009).

The review of the NHS introduced the concept of commissioning for quality and innovation (CQUIN) (Darzi, 2008), where providers will be financially rewarded under their contracts with PCTs for demonstrating quality via three indicators: patient safety, effectiveness and patient experience (Department of Health, 2008b) with PCTs developing what a local CQUIN scheme would look like and working with providers to agree exactly what would be included in the resulting annual quality accounts (Department of Health, 2008c). This new scheme of measuring quality of providers, via improvements made as a result of responding to patient experience feedback, produced a differentiation in the way the views of patients are used (Department of Health, 2009c). Provider organisations would use the information to demonstrate they have made changes to services as a result and that their patients are satisfied with the services provided. Commissioners would use the data provided by the healthcare providers as part of performance management and using their own analysis of patient feedback to inform commissioning decisions.

Meanwhile, the metrics of performance managing PCTs around the world class commissioning competencies put an emphasis on sustained engagement with patients, the public and community groups (Department of Health, 2007b). Polling and stakeholder surveys asked the public and partners whether “The PCT proactively engages my organisation to inform and drive strategic planning and service design” (Department of Health, 2008a:40) and patient perceptions on whether they feel they can influence decision-making.

Gordon Brown, the then Prime Minister, talked of giving people “power” to transform services, ensuring that public services respond to the voice of local people to ensure that services meet their needs (HM Government, 2009). However, a survey of health advocacy groups described a picture of confusion around the ‘local’ healthcare commissioning process, with the complexity and the bureaucracy of the process putting patients off getting involved or understanding how they can make a contribution. The patient groups contacted saw themselves as having an untapped expertise in the views of patients, however respondents appeared to have experience of PCT commissioning, deeming practice based commissioning to be ‘local’ and needing improvement in their involvement (PatientView, 2009).

The NHS Constitution was published in 2009 (Department of Health, :3, 7), describing rights and responsibilities for patients coupled with values, pledges and commitments for the NHS. It makes a pledge regarding PPI:

*“NHS services must reflect the needs and preferences of patients, their families and their carers. You have the right to be involved, directly or through representatives, in the planning of healthcare services, the development and consideration of proposals for changes in the way those services are provided, and in decisions to be made affecting the operation of those services. The NHS also commits: to provide you with the information you need to influence and scrutinise the planning and delivery of NHS services (pledge).”*

In the summer of 2009, the NHS Centre for Involvement closed, due to the end of the contract with the Department of Health (The NHS Centre for Involvement, 2009). A study by the Healthcare Commission concluded that “there was limited evidence of how people’s views were used to improve services” (Healthcare Commission, 2009:86). The NHS Next Stage Review focused on the need for change to be clinically driven and led making little reference to the voice of the patient in indentifying the changes to be made (Next Stage Review Implementation Team, 2009). A review of PPI, which included practiced bases commissioning, found that again, there is little evidence of public engagement, PPI is given a low priority and there is confusion and disagreement in how PPI can or should be embedded in the commissioning process (Coleman et al., 2009).

There is not “sufficient evidence that people’s needs and views were the significant drivers behind many of the changes being made to health services” (Healthcare Commission, 2009:77) and yet it has been shown that there is no formal measurement of what successful influence or change would look like.

Section 11 of the Health and Social Care Act (Parliament, 2001) and the policy guidance in place at the time of the study (Department of Health, 2003d) focussed on a duty to set up processes to involve and consult users of services. Across the country, and within WNPCT, this led to a focus on PPI *activity*. Even the Practice Guidance for Section 11 (Department of Health, 2003e), provided a toolkit on the *how* of doing PPI activity, rather than the change management process that would be needed to ensure that action was taken as a response to what had been said. There was no formal indication of what good performance looked like in terms of outcomes. One of the key competencies of a world class commissioning organisation is the engagement of patients and the public. PCTs are expected to be able to see the impact that has had and demonstrate improvements in peoples health and experience of services. To gain the highest level of competency, patients, through polling by research companies commissioned by the SHA, must strongly agree that the local NHS

listens to their views and “acts in their interest” (Department of Health, 2009a:77). The focus was now on using the patient experience data from providers to steer commissioning, whereas the PCT itself must have working relationships in place with the local community, such as LINks, embedded into the commissioning process and driving decision-making.

## **2.3 Local policy development**

Having discussed the national policy context for the study, the development of patient and public involvement since the establishment of West Norfolk Primary Care Group (WNPCG) is now reviewed.

It is clear from the document review that a plethora of documents, strategies, policies and minutes purported to support the value of PPI. There is a common thread running throughout that stresses the importance of carrying out PPI activity, from induction through to staff training and the need to report activity on a public database. This section provides a chronological history showing the development of the local policies and the role of Public Involvement Manager (PIM).

In 1998 a new part-time role of Health Events Officer was established within the Communications Directorate of the North West Anglia Health Authority, funded following the White Paper (Department of Health, 1997) and line-managed by the Health Promotion department (North West Anglia Health Authority, 1997), a role I was successful in securing. The main responsibilities of the role were, as the job title suggests, to initiate and co-ordinate health events with the aim of increasing patient education and awareness of healthy lifestyle choices.

In line with the drive from national policy (Department of Health, 1999a), West Norfolk Primary Care Group (WNPCG) took over the employment of the



Health Events Officer post in 1999, with new responsibilities for beginning the process of involving local people in the decision-making (Copsey, 1999).

In their new PCG launch press release (West Norfolk Primary Care Group, 1999a) the PCG Chairman confirmed that the PCG was investigating ways in which patients could be involved in local decision-making around West Norfolk health services. The PCG played a role at this stage nationally in an early pilot workshop designed to highlight the public involvement needs for PCGs (Copsey, 2000). Activities for the Health Events Officer included working with the local Health Forum, encouraging patient participation groups in general practice and utilising the Citizens Panel (Copsey, 1999). Overall accountability for public involvement was given to the then Heads of Service Development and Primary Care.

West Norfolk PCG Board expressed an interest in exploring a move to PCT status in June 1999 and put the proposal to public consultation on the issue in September of that year. Over 30 consultation meetings were held by the Health Authority over a period of two months across West Norfolk with staff, patients and carer groups attending, including North West Anglia Community Health Council (Daniels, 1999; West Norfolk Primary Care Group, 1999b).

The consultation paper that accompanied the meetings above talked of meeting the needs of patients and stated as a reason for becoming a PCT, the ability to “be responsible to local needs expressed by local people” (West Norfolk Primary Care Group, 1999c:5). Expanding upon how the PCT would garner patient views, the document pledged to have “sustained public involvement in the planning and development of services” and saw this as happening through PCG Board meetings held in public, borough council representatives and lay representatives on Boards, developing the relationship with the CHC, complaints and a “programme of public involvement”(West Norfolk Primary Care Group, 1999c:8).

In the meantime, the PCG made initial efforts to begin the public involvement process. The PCG Board discussed the issue of questions from the public during Board meetings and agreed to allow open questions at the beginning, with the Chair able to interrupt meetings if appropriate, to enable the public to speak (West Norfolk Primary Care Group, 1999b). Under the umbrella of clinical governance, the PCG ran its first survey within the auspices of the Local Authority via the Citizen's Panel to gauge patient experience of local GP services (Jones, 1999).

By May 2000, and again reflecting the national direction (Department of Health, 1999a), the Health Events Officer role had evolved into a 'Public Involvement Officer', with a remit for implementing and coordinating PPI activities (Copsey, 2000). Three months later, West Norfolk PCG advertised internally the part-time role of Public Involvement Manager, explaining the wish to extend the position from a fixed-term contract to a permanent position with a promotion from an 'admin and clerical' grade to senior management (West Norfolk Primary Care Group, 2000b). The role was to provide support to the PCT in "leading the strategic development of public involvement in primary care" and to "facilitate the involvement of local people in the planning and development of health care and wellbeing issues as active partners with professionals" (West Norfolk Primary Care Group, 2000c:). Again, I was successful in securing this post.

Following the publication of the *NHS Plan* (Department of Health, 2000), the PCT published its first Public Involvement Strategy in 2000 (Turner). To increase capacity and in acknowledgement that PPI could no longer be 'one person's job', the PCT introduced its first public involvement training in 2001. Training in facilitation skills was provided, primarily for PCT staff, but also offering the opportunity to the multi-agency Public Involvement Team members to enable them to have a core group of facilitators within each organisation (Turner, 2001a). Training was also offered by the PCT to instruct new and existing trainers from the Public Involvement Team in how to deliver

the College of Health's *Voices in Action* workshop to enable them to deliver the course in 'how to have your say' to members of the public (Turner, 2001f).

In 2003, and again in 2004 and 2005, (Turner, 2004b, 2005) the local strategy was revised and adopted by both the PCT Board and the local acute Trust, providing a strategy for the whole health economy. The strategy described nine guiding principles of public involvement: maintaining and sustaining systematic public involvement in the operation of the PCT; ensuring timely activity to provide the opportunity for giving views; networking and sharing good practice; inclusivity of those groups and individuals the NHS finds 'hard to reach'; resources to support involvement; innovation; accountability, feedback and evaluation of the PPI methods used. The strategy talked of accountability and public opinion affecting change within the PCT and stated that the PCT would feed back:

- *What has been done as a result of what has been said?*
- *What is going to be done and when?*
- *What is not going to be done and why?* (Turner, 2004b:9)

However, the majority of documents reporting PPI activity appear not to fulfil this feedback and accountability pledge, with no reports available of what happened, or not, as a result of the PPI. This emphasis of feedback was later reflected in CHI's findings and recommendations (Commission for Health Improvement (CHI), 2004) and those of the Department of Health (2004a), refocusing Trusts on the outcomes of PPI work, as opposed to the existing 'tick-box' paradigm, as discussed earlier.

WNPCT also devised an out-of-pocket expenses policy for public involvement to reimburse patients, carers and members of the public their travel costs, carer and childcare costs, in cash, on the spot at PPI events (Turner, 2001g). This pre-empted the Bristol Royal Infirmary Inquiry, which also recommended reimbursement to ensure the public was not prevented from participating due to

financial constraints (Bristol Royal Infirmary Inquiry, 2001). The documents show that the reimbursement procedure was regularly utilised as standard practice for PPI.

In 2002, WNPCT signed the Norfolk Compact (Norwich and Norfolk Voluntary Services (NNVS), 2002) agreeing to a framework of consultation that would enable the voluntary and community sector to participate in 'partnership' on local policy-making. The ethos of PPI was introduced into the PCT's staff induction programme at the beginning of 2003 (West Norfolk Primary Care Trust, 2002b), however there is no evaluation of the impact this had on staff.

*Voices in Action* training was delivered to patients, carers and members of the public who were members of the PCT-led committees and planning groups (Turner, 2002). Initially offered to adults, the PCT worked with young people to develop a training package '*Trust me, I'm a Patient*' for young patients (Turner, 2004).

With the introduction of the *Health and Social Care Act* (Parliament, 2001), the PPI workload was increasing and a case was put forward to increase the hours of the role to full-time to reflect the true extent of the work (Turner, 2002). This was implemented in May 2003 (West Norfolk Primary Care Trust, 2003b) and my role of PIM became managed by the Deputy Chief Executive.

Regionally, Norfolk, Suffolk and Cambridgeshire (NSC) Strategic Health Authority (SHA) devised their own public involvement strategy in collaboration with Trusts such as WNPCT within their area via the SHA Public Involvement Network (Hague, 2003:5). The document supported and emphasised the requirement of public involvement, and stated the SHA's role in performance managing Trusts was to ensure PPI was effectively undertaken, once again, demonstrating a focus on PPI activity. In addition, the document emphasised that PPI should not be perceived as requiring extra resources,

neither financial nor human. This could be seen as suggesting that PPI was a core function of a PCT and therefore an integral part of funding. Alternatively, the lack of resources could also be perceived as a contradiction to the purported value and necessity of PPI.

In 2003 WNPCT created its own training session entitled ‘Public involvement (PI) – The Basics – why you?’ encompassing the national and local drivers for PPI, the exploration and challenging of attitudes and behaviours, identifying barriers and finding solutions to overcome them, examining the different levels of PI and their appropriateness and providing some practical tools for putting PI into practice (Turner, 2004a) . This training was delivered to PPI leads across the NSC SHA at their request as an example of good practice for them to deliver within their own Trusts (Norfolk Suffolk and Cambridgeshire Strategic Health Authority, 2005b).

By March 2004 the job description was changed again, this time to include the responsibility for engendering a culture change towards integrating PPI within the PCT (West Norfolk Primary Care Trust, 2004d). This included developing a local PPI strategy for the whole of the West Norfolk health economy, interpreting national health policy in relation to PPI and encouraging the ethos of PPI at Board level and across the PCT.

From the ad-hoc provision of PPI training, the PCT developed a formal programme which offered instruction to staff in the basics of public involvement, then training in the tools to put PPI into practice, including facilitation skills, patient questionnaires and discovery interviews (Turner, 2004d).

West Norfolk PCT signed up to the county-wide Public Involvement Forum formed by Norfolk County Council in 2004, which in turn produced its strategy for “*Active and Engaged Communities*” in 2004 encompassing four key targets, with a focus on the PPI activity, rather than responding to the outputs:

1. *Increasing interest and belief in public participation*
2. *Increasing the opportunities for people to be involved*
3. *Increasing individuals and communities ability to get involved*
4. *Improve the quality of public involvement*

(Tansley-Thomas, 2004:3)

Patient Partnership (NHS Executive, 1996) was one of the functions transferred from PCG to PCT. Under this banner WNPCG, in conjunction with North West Anglia (NWA) CHC, held a workshop of local people in 1999 to discuss how West Norfolk patients could be involved in decision-making around health issues and the local health service (West Norfolk Primary Care Group, 2000a). As a result of the workshop, a new West Norfolk Patient Partnership (WNPP) group was formed, chaired by a lay person and now comprising of representatives from Patient Participation Groups (PPGs) in local surgeries across West Norfolk. WNPCT provided administration with public involvement staff from the local acute Trust and the PCT attending to provide two-way communication and resolution of issues raised (West Norfolk Patient Partnership, 2004).

Other avenues for the public to be involved included the West Norfolk Health Forum, chaired by NWA CHC, administrated by the local authority, with a remit for looking at national and local health improvement policy in general. Community and voluntary groups also met under the umbrella of the West Norfolk Community Forum, which was chaired and serviced by the local Association of Voluntary Organisations, later to become the Council for Voluntary Services (CVS) (Turner, 2000c). It was argued that there was a public perception of confusion and duplication in the plethora of public involvement in health fora in West Norfolk. At a subsequent meeting to address this issue, the facilitator from Norfolk Health Authority congratulated West Norfolk for having an “embarrassment of treasures” in terms of its public involvement (West Norfolk Primary Care Trust, 2001d:1). Although there was

recognition that there was duplication and a potential for amalgamation, this was not to be the outcome and each group continued as before.

Recognising a need to work with other statutory agencies, reduce duplication of effort and share good practice, West Norfolk PCT formed a multi-agency Public Involvement Team in 2000. This comprised of key staff members in partner statutory agencies with a remit for involving the public in decision making (Turner, 2000d; West Norfolk Primary Care Trust, 2000). Membership included all tiers of local authority, social services, health, education, police, fire services and the local CVS. This Team went on to become the formal public involvement arm of the West Norfolk Partnership, also known as the Local Strategic Partnership (LSP). In the Public Involvement Team's terms of reference, they cited working together to integrate public involvement into everyday policy, planning and service delivery of the member organisations (West Norfolk Public Involvement Team, 2005).

The PCT outlined its commitment to PPI in each of its annual reports (West Norfolk Primary Care Trust, 2001a, 2002a, 2003a, 2004a) and all non-executive directors were given the task of championing PPI. The PCT's Local Delivery Plan (LDP) highlighted PPI as one of guiding values for the vision of the PCT and identified improving the patient experience as a key priority (West Norfolk Primary Care Trust, 2005b).

With the announcement of commissioning a patient-led NHS (Crisp, 2005), further developments in PPI within West Norfolk were halted as the focus turned to reconfiguration of PCTs to meet the national requirement of reducing their number.

## 2.4 Reconfiguration

Turning from the national PPI issues to more practical concerns of a reconfiguration of the structure of the NHS that underpins the role of PPI in the NHS, “*Commissioning a patient-led NHS*” (Crisp, 2005) announced the drive for a reconfiguration and reduction of the number of PCTs and SHAs to allow the move from a “provider driven service to a commissioning driven service”, with changes in place by December 2006, just 13 months later (see timeline below). The reduction in PCTs was also to enable a 15% reduction in management and administrative costs. With a focus on commissioning from a range of providers, rather than PCTs directly providing healthcare, this paper introduced the concept of a ‘provider/commissioner split’, with the PCT role in service provision reduced to a minimum by December 2008. In addition, Practice based Commissioning (PbC) would be put in place and PCTs would go through a rigorous assessment process to ensure they were ‘fit’ for the purpose of commissioning.

Reconfiguration timeline	
July 2005	‘Creating a patient-led NHS’ published
October 2005	SHA plans for reconfiguring PCTs submitted
March 2006	Consultation completion date
October 2006	PCT reconfigurations completed
April 2007	SHA reconfiguration completed
December 2008	Changes in PCT service provision completed

**Table 2.4: Reconfiguration timeline** (Crisp, 2005).

NHS Trusts would begin the move to Foundation Trust status and the ambulance Trusts would reconfigure by March 2007.



Although a surprise to some PCTs (House of Commons Health Committee, 2006), debate had already taken place nationally regarding the ability of PCTs to challenge the hold of acute trusts on driving commissioning and local decision-making in the current format versus critical mass of a larger organisation and the relationship between size and performance (Gershon, 2004; Peck and Freeman, 2005). However, the conclusion drawn was that there was no significant benefit from having larger PCTs, neither in terms of cost savings nor for improvement in commissioning and contracting negotiations.

In a core script for NHS communicators targeting primarily NHS managers, organisational change was to be explained in terms of PCTs needing to 'concentrate' on commissioning and stressed by underlining, that some PCTs had not been effective and that PCTs would only continue to directly provide services "if that is what's best for patients" (Bailey, 2005).

The demand for a rapid reconfiguration of PCTs was highly criticised, not only for the lack of warning and debate, but also for the impact that it would have on staff morale, the day-to-day business and patient care, as change on this scale is known to take 18 months to settle. The lack of patient and public involvement prior to the publication of '*Commissioning a patient-led NHS*' (CPLNHS) met with disapproval together with concerns regarding the impact on PPIFs, which were linked to the existing PCTs. In particular, the confusion and lack of clarity around the divestment of provider services was the most significant concern, claiming that 'form' had come before 'function' (NHS Alliance, 2005; House of Commons Health Committee, 2006). Responding to the threat of judicial review by the Royal College of Nursing, the Secretary of State for Health stated that there is no policy or timetable for divestment of provider services by PCTs (Hewitt, 2005a), which was seen as a retreat from the original proposal (White and Carvel, 2005).

The Government's response to the criticism (HM Government, 2006) restated their belief that bigger and fewer PCTs would improve commissioning and provide improved relationships with local authority by co-terminosity of boundaries. Regarding PCTs divesting of their provider arm, the Government clarified that they would not instruct PCTs to do so, nor impose a timeline, although contradicting *'Commissioning a patient-led NHS'*, this was cited as an example of listening and responding to views since the announcement. However, they provided a caveat later in the paper that, should PCTs "fail" the test of ensuring value for money, quality and equity in service provision, then divestment would need to take place.

On the same day the PCTs received news of their impending reconfiguration, the Secretary of State for Health announced the next steps for a consultation on care closer to home: *'Your health, your care, your say'* (Hewitt, 2005b), promising to involve patients and the public. The subsequent white paper *'Our health, our care, our say'* (Department of Health, 2006c) talked of an emphasis for PCTs on commissioning and monitoring services from a range of providers and for the PCT to review the provider 'arm' of the PCT to consider new models of delivering care, separate from the organisation, such as a not-for-profit company.

Provider reform was further detailed (Department of Health, 2006b) with a focus on PCTs commissioning from a range of service providers to offer choice for patients and allowing healthcare providers to meet that new challenge.

Regional consultations on CPLNHS were criticised for not involving local people, which can give PPI "a bad name" (House of Commons Health Committee, 2007a).

As the reconfiguration proposals progressed, national commentators focussed on the potential high number of job losses and the cost of those losses in both financial and morale terms (Carvel, 2005; Donnelly, 2005; Harding and

Mooney, 2005; Health Service Journal, 2005; Young, 2005; Donnelly and Moore, 2006).

The conclusion of the reconfiguration resulted in the reduction of PCTs to 152 from 1 October 2006. In line with the national direction, WNPCT became part of the reconfiguration process to potentially merge the neighbouring PCTs of South Norfolk, North Norfolk, Norwich, Broadland and Great Yarmouth and Waveney.

Following the announcement of '*Commissioning a patient-led NHS*' (Department of Health, 2005a) in July 2005, Norfolk, Suffolk and Cambridgeshire Strategic Health Authority (NSCSHA) submitted its proposal for the future reconfiguration (Norfolk Suffolk and Cambridgeshire Strategic Health Authority, 2005). The document discussed the need to have large enough organisations to be effective commissioners at the same time as ensuring they would be able to respond to local need. The paper admitted that the NHS organisations and stakeholders across the patch were unable to reach consensus, however the submitted preferred option was for one PCT in Norfolk, with co-terminosity with Norfolk County Council.

WNPCT agreed with other Trusts and stakeholders in the area following local consultation that, if unable to remain WNPCT, their preferred option was for three PCTs in Norfolk. This would see WNPCT merging with North Norfolk and Breckland PCTs (Norfolk Suffolk and Cambridgeshire Strategic Health Authority, 2005a). In the midst of this, WNPCT was advertising for a project manager to lead the reconfiguration of PCTs together with the Chief Executive. I applied and was successful in securing the post, which meant that my PPI role was reduced to part-time, whilst my focus, and indeed that of the majority of staff, was more inward facing and PPI activity reduced considerably.

In December 2005, the consultations began across the county. The NSCSHA document provided two options for the future configuration of PCTs in the area,

both having similar outcomes for WNPCT. They would become part of a Norfolk PCT covering the whole county, or a Norfolk county PCT minus Great Yarmouth and Waveney. Five public meetings were held across Norfolk, with a further 22 meetings with stakeholders, such as MPs, staff, provider Trusts (Norfolk Suffolk and Cambridgeshire Strategic Health Authority, 2006).

The outcome was a Norfolk PCT, minus Great Yarmouth and Waveney, which was formed on 1 October 2006. Initially, directors had to apply for new posts, whilst all other staff transferred across via TUPE arrangement. Directors then drew up their new structures and over a period of some months, staff was recruited to new posts. It is within this new organisation, now rebranded NHS Norfolk, that I secured the post of Head of Communications and Patient and Public Involvement and in 2009 I became Director of Communications and Engagement.

## **2.5 Liberating the NHS**

At the cusp of this thesis being finalised, and with a backdrop of global financial constraints, the new Conservative/Liberal Democrat coalition Government has announced another change to both NHS organisations and PPI structures (Department of Health, 2010). They claim that the voice of patients and the public will be made more powerful through reinventing Local Involvement Networks as HealthWatch and PCTs will be abolished and replaced by clusters of GPs that will be expected to commission healthcare services for their local population. A range of other proposals include the abolition of SHAs, the formation of an independent national Commissioning Board, transferring responsibility for public health to local authorities with a focus on improving healthcare outcomes, and giving more autonomy to foundation trusts. At the time of writing, these proposals are going through a period of national public consultation, so I do not intend to cover this new development in depth. Instead, I leave this review at a time of further

significant change and challenge for the NHS and return to this only in my final chapter where recommendations for policy and practice are made.

## **2.6 Chapter summary**

From my analysis of the literature, I conclude that there appears to be a ‘brick wall’ between the framework and activity of PPI - the outputs - and the influence of those outputs in healthcare planning and decision-making that lead to actual change to service delivery and patient care as a result – the outcomes (Commission for Health Improvement (CHI), 2004). At the time of the fieldwork for this study (2004) the DH response to this conclusion (Department of Health, 2004a) gave no insight into what had enabled those organisations and staff in their examples to engage in that change. Nor did it indicate if these examples were ‘one-off’ events or indicative of PPI leading the change across the entire organisation. Furthermore it failed to provide an insight into how the wall could be ‘broken down’ to prevent a continuous rescaling of the wall by each NHS organisation. It was argued by the policy makers, commentators and researchers alike that there was a need for a culture change within the NHS, to enable PPI to be implemented and become integrated into service design, planning and delivery, but offered no clear indication of how this could be enabled.

Studies researching the issues of PPI had used a range of qualitative research methods focusing on the patient perspective of their involvement in PPI activity, the extent of user involvement in health and the use of public involvement techniques, staff education and training and patient involvement in the decision-making process around individual patient care (Anthony and Crawford, 2000; The School of Health and Related Research (ScHARR), 2000; Crawford et al., 2002; National Consumer Council (NCC), 2002b; Thompson et al., 2002; Birchall and Simmons, 2004; Farrell, 2004; Department of Health,

2005d). South (2004:131) identified the need to explore the impact of public involvement on planning and decision-making in the four PCTs she studied, however the only reference she makes regarding her findings on this is where she says "...there were many areas where community influence had been felt." Studies such as these mainly served to report that the PPI policies have had little effect in terms of bringing about change. A key shortcoming in this area was the paucity of research into **how** this change can be implemented as a response to PPI.

Moreover, from the PPI activity researched above, it is clear that patients, carers and the public have played their part in the process by expressing their views and opinions and explaining what they would like to see changed. In these cases, the public are prepared to get involved and are willing to see those changes in outcome. They are not in themselves preventing the change in healthcare or service delivery that could follow so are not part of the brick wall. Ergo, it remains that the organisation and/or the staff within the organisation are the blocks in the process. In order to identify how PPI can influence planning and decision making, there is a need to know more about why the current situation exists.

In summary, this chapter has provided a critical chronological history of the development of national patient and public involvement (PPI) policy, examining the role of patient representation via community health councils, the growth of consumerism through to the present day policies and legislation of PPI. It has been established that the NHS, although expressing commitment to the values of PPI and having the relevant structures in place, hit a 'brick wall', where the views of the patients do not appear to be influencing changes and improvement in patient care, service delivery or the patient experience. A local context was also provided, describing the policy development within West Norfolk PCT through to the period of reconfiguration. Finally, proposals for further major change to the NHS are being consulted on and a brief mention is made of this.

In conclusion, national commentators and legislators alike have talked of the need for a culture change, a change in the way services are planned and delivered, a change in staff attitude and the way professionals work with patients, if the NHS is to become truly responsive to the views of local people. However, PPI is still seen as ineffective with the outputs of PPI activity not leading to outcomes in terms of changes in healthcare services. There continues to be a 'brick wall' between the outputs of PPI activity and the change that was made as a result – the outcome. There remains a gap in knowledge regarding how primary care trusts can enable patient and public involvement to lead to changes in health services. In the next chapter, the methodology for this research study is considered in the light of that gap in knowledge, justification is made for the methodology and issues of rigour, validity and ethics are discussed.

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## **CHAPTER 3: RESEARCH METHODOLOGY**

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### **3.1 Introduction to the topic**

Chapter 2 provided the policy context and identified the research question. In this next chapter I first provide and justify the methodology used to provide data to investigate the research question, then I describe the research method. My intention here is to describe my journey and process of elimination as I identify and reject the various choices and options at my disposal to approach this study. Beginning with the assertion of my ontological position, I continuously hone down until I am able to specify the methodological framework I used.

### **3.2 Quantitative or qualitative research?**

Although aware of the philosophical and ideological underpinnings of the methodologies available to me, my choices were made in a more pragmatic way. When I commenced this study, I began with a method in mind with which I was most comfortable, knew well and broadly used; namely interviews with individuals where I listen and note perceptions, and facilitated meetings of groups of individuals. Having decided on that, I sought a methodology that incorporated that approach to data and a process of data collection that would allow me to make sense of it. In discussions with my PhD supervisors at the time and through my own reading, I was steered towards action research. Upon further reading and understanding, I was able to hone my options and came to an agreement that AR was the best suited methodology for my study.



The decision of which methodological approach to take is fundamentally driven by ontological and epistemological paradigms. A simple explanation of these terms is provided in table 3.1 below:

Ontology	What is the nature of reality?
Epistemology	How can we be sure that we know what we know?
Methodology	How can we go about finding things?

**Table 3.1: Philosophical definitions** (Adapted from Guba and Lincoln (1989:83)).

A positivist philosophy has three key elements; there is one true explanation for the issue being studied; that there is one method of inquiry, namely cause and effect; and that knowledge is free from subjectivity, perspectives and is true (Guba and Lincoln, 1989). The ontological position for this social inquiry study is one that contends there are multiple realities, socially constructed, with no one truth. Ontologically, my research could not help but be subjective and coloured by my prior understandings, assumptions, convictions and beliefs. As an insider researcher I could not disassociate myself from the investigation and nor would I wish to. Any data I obtained would be filtered through my own experience and values. When researching social processes - why someone thinks as they do, or behaves in a particular way, there appears to be a number of 'truths' as perceived not only by the participants or those being observed themselves, but also as perceived by the researcher, and potentially by the audiences reading the observations and analysis (Butler, 1997). I might well perceive these differently through my use of language, my experience, my gender, my own values and beliefs. In social inquiry, belief can alter observation (Fay, 1987).

The philosophical approach, therefore, needed to be one that accepted the researcher as part of the world, interacting with others. I would be examining my own practice and the role I had working with other members of staff in my

own organisation. Epistemologically, any findings would be coloured by my personal understanding and my knowledge, filtered through my perceptions, values, beliefs and experiences, therefore any approach needed to reflect this. I cannot be dispassionate about my research, nor would I wish to be; therefore a positivistic approach would not have been possible, as I could not provide the necessary objectivity and value-free perspective. This constructivist stance determined the approach to my choice of a quantitative or qualitative research methodology.

Kirk and Miller (1986:9) provide a definition of qualitative research where quality is defined as “the nature of the thing” or the degree to which a feature is present, as opposed to quantitative research which they define as “the amount of a thing the presence or absence of a thing”. A positivistic or scientific approach to the type of research question that address beliefs, attitudes and change in practice is not usually appropriate (Easterby-Smith et al., 2002). Instead, a more interpretivistic approach was required, as I sought illumination and understanding to help improve my own practice and that of others.

The philosophical approach needed to embrace the need for understanding the values and beliefs motivating any actions (Carr and Kemmis, 1997) and the nature of PPI within my organisation. Carr and Kemmis (1997:88) argue that motives and interpretation are intrinsically linked to actions and that therefore a positivistic approach, which they describe as being “denuded” of meaning, cannot assist in understanding or interpreting the motive of an actor.

The chosen methodology also needed to be able to tackle the issue of change and changing practice which has been highlighted as key to the research issues. The exploration for this type of study is best suited to a qualitative methodology that is concerned with identifying the factors that contribute to successful or unsuccessful outcomes and how the situation occurred (Spencer et al., 2003). Qualitative research is also used where there is potential to improve practice (Marshall and Rossman, 1995).

In addition, Dick (2000:1) claims that “good research is designed to fit the interests and skills of those involved and it is partly created by and helps to create the research situation and the research questions.” Furthermore, it is argued that researchers should choose a research paradigm or conceptual framework that is consistent with the researcher’s own view (Thompson and Perry, 2004). In this study, both my skills as a Public Involvement Manager and my principle for the need to understand the opinions and views of participants in any study substantiate the need for the use of a qualitative methodology.

Finally, Morton-Cooper (2000:8) refers to the scientific quantitative ways of doing research in a healthcare setting as creating boundaries which puts participants into the role of “passive and relatively powerless consumers”, which would be antithesis for a study that aims to investigate why the outputs of patient and public involvement do not influence decision-making.

Given the above and taking into account my philosophical paradigm, the type of social issue the study is addressing, the potential for the findings to improve practice and influence policy, and my own experience and skills, I deemed a qualitative research methodology to be concordant.

Having decided to use a qualitative methodology for this study, attention was then drawn to narrow down further the choices available within this given approach and in this next section I provide an overview of the pragmatic options I considered.

### **3.3 What type of qualitative research?**

Miles and Huberman (1994) argue that taxonomies of qualitative research are conflicting, unhelpful and become out of date very quickly.

With no clear catalogue of research from which to choose, I considered four realistic options that would potentially be suitable for the context within which I was both working and studying. If I was to research and improve my own practice and identify what action was needed to break down the wall brick by brick, then I needed to find a research framework that (a) accepted a researcher on the 'inside' of the organisation being studied, (b) would embrace learning through action and (c) employed a method of asking 'why is this...?' and 'what if...?' questions rather than 'how many...?' and putting theory into praxis (Habermas, 1973; McNiff et al., 2003). The four pragmatic options I considered were ethnography, case study, grounded theory and action research. I now consider each of these in turn.

### **3.3.1 Ethnography**

Ethnography was originally developed by anthropologists studying a culture or society, and often requires the researcher to "spend time in the field" becoming integrated into the population in which they were studying (Denscombe, 1998:68-69). Every day life, including the routine, is considered research data with a focus on "how the members of the group/culture being studied understand things". Much emphasis is placed on reflexivity and the researcher's subjectivity as they filter their perceptions through their own world view (Brewer, 2006). Advantages of an ethnographical research methodology is that there is direct observation and empirical data, however the researcher's subjectivity is a drawback here, causing a "blind spot", obscuring a vision of "the obvious" (Denscombe, 1998:80). Moreover, when a researcher is already an insider, there is an expectation that they will mentally distance themselves from the field (Oliver, 2004). For this study, I needed a methodology that would consider my 'insiderness' as a researcher studying my own practice, my own experience, knowledge and perceptions an advantage, so on this basis I rejected ethnography.

### **3.3.2 Case study**

A case study methodology allows the researcher to “focus on one instance (or a few instances) of a particular phenomenon with a view to providing an in-depth account of events, relationships, experiences or processes occurring in that particular instance.” (Denscombe, 1998). The advantage of using this methodology is that it can be used to answer the ‘how’ and ‘why’ questions posed and would enable me to place a spotlight on the complexity of the situation, using multiple data collection methods to allow triangulation (Hartley, 2006). However, once again the researcher as an insider is not embraced and researchers are expected to be wary of the observer effect on participants, where they behave differently when involved in an experiment of some sort. In addition, the justification for using one site has to be robust, with clear justification for how that site is similar or different to others to allow the findings to be generalisable. In my study it is my own practice that is being researched and the site is my own organisation and therefore a methodology is required that recognises and accepts the research of ones own practice. On this basis, a case study methodology was excluded.

### **3.3.3 Grounded theory**

Most research requires the testing and validating of a preconceived theory, whilst a grounded theory approach focuses on creating social theory from a systematic collection of empirical data (Lansisalmi et al., 2006). Glaser and Strauss (1967) claimed that theory created in this way, a methodology they designed during their study of terminally ill patients, is superior to that of traditional research approaches, claiming that their process of constant comparison of data and concepts emerging from the data until saturation is reached avoids the risk of researchers developing an inappropriate theory that suspiciously fits with the results they expected or were hoping to find. Although later Glaser and Strauss become divided on how grounded theory is

implemented, the basic tenet of data producing theory through data remains. The premises are that the researcher approaches the study with an “open mind”, with no identification of the sample at the commencement of the study and the data analysis is “pragmatic” and “geared towards generating new concepts and theories” which are “grounded in empirical reality” (Denscombe, 1998:214-216). The claim that this methodology can generate theory is disputed by Thomas and James (2006) who argue that to generate theory only from the data, ignores and dismisses the prior understanding, views and knowledge brought by the practitioners.

In my own study, the research question is specific, is based on my own understanding and experience and suggests a pre-designed sample. In addition, the authors claimed that only professionally trained sociologists can develop theory using grounded theory that others will then apply (Glaser and Strauss, 1967). The process of saturating data by its nature makes determining an end point for the study difficult, and for pragmatic reasons my own study needed to be time limited. I rejected grounded theory as a methodology on these grounds.

### **3.3.4 Action research**

Many authors agree that ‘action research’(AR) is a confusing term (Hart and Bond, 1998; Hampshire et al., 1999; Meyer, 2000b; Waterman et al., 2001; Coghlan and Brannick, 2003; McBride and Schostak, 2003), but in essence, AR is the “idea that if you want to understand something well, you should change it” (Easterby-Smith et al., 2002:8). AR is “improvement of a practice,... of the understanding of a practice by its practitioners and the improvement of the situation in which the practice takes place” (Robson, 2003:215).

Waterman et al., (2001:iii) define AR as “a period of inquiry that describes, interprets and explains social situations while executing a change intervention aimed at improvement and involvement” while Meyer (2000b:178) argues that AR is a “style” rather than a methodology. AR is described as being about

changing practice and reflecting on learning (Elliott, 1991; Kemmis and McTaggart, 1997; McNiff and Whitehead, 2006), focussing on self-enquiry.

Kurt Lewin (1946) is generally credited with originating the term 'Action Research' (Kemmis, 1993; Waterman et al., 2001; McBride and Schostak, 2003). When studying intergroup relations his observation was that people want to do something to change and improve a situation, but do not know where to start. He argued that those affected by change should have the responsibility to take action and that "cooperation between practitioners and social scientists is key" (Lewin, 1946:39). He considered AR to be a scientific method of problem solving, whereas others disagree, claiming that AR does not follow the positivist paradigm of social research and is mere common sense (Susman and Evered, 1978; Schwandt, 1997). Others argue that the AR 'spiral' strategy (described later) is more important than the "scientific detached view" (Williamson et al., 2004).

Denscombe (1998:57) summarises the four defining characteristics of AR:

- Practical – dealing with real issues, typically within an organisation.
- Change – both in terms of dealing with a practical problem to improve practice and as a means of investigating a problem.
- Cyclical process – taking action, measuring, investigating, evaluating and planning for further action.
- Participation – of the practitioners and those involved in the research.

One of the disadvantages is the lack of impartiality on the part of the researcher (Denscombe, 1998). Consideration on whether or not the researcher should be a participant in the research, and whether or not they should maintain their distance from the material that is being researched, is important here (Waterman et al., 2001). There is a school of thought that if a researcher is carrying out enquiry into the situation in which they themselves are working, then it is "virtually impossible" and "ineffective" to remain 'outside' and

‘external’ to the research (Robson, 2003:7). This is particularly pertinent for the site of this research and me as the researcher and further justifies the use of action research.

However, by using AR the insiderness and subjectivity of both the researcher and the participants is embraced (Morton-Cooper, 2000:9); (Easterby-Smith et al., 2002:33). Conversely, Waterman et al., (2001) found that from the 59 AR projects in health they studied, feedback regarding an insider researcher rather than an outsider was perceived as having more negative aspects, for example in terms of participants’ reluctance to disclose information or feeling vulnerable about their involvement if the researcher was perceived to have their work sanctioned by those in authority. While not prohibiting using insider researchers, this means that the researcher needs to take steps to behave ethically and ensure that these steps are written into the project proposal to increase the ethical rigour (see 4.6).

There is a further dilemma for the researcher of their affecting what is being examined by the very interest that is shown in the participant, the so-called ‘Hawthorne effect’, (Mayo, 2003), as was mentioned earlier regarding ethnography, and also the potential of exploiting participants (Easterby-Smith et al., 2002). However, in AR this very involvement is considered a strength and is supported by the belief that the people who are likely to be involved in implementing any changes, or indeed affected by the changes, **should** become involved in the research process (Easterby-Smith et al., 2002).

Action research is particularly useful where the problems preventing implementation of change can be studied and solutions sought (Marshall and Rossman, 1995; Robson, 2003). AR is claimed to help “practitioners, managers and researchers make more sense of problems in service delivery and promoting initiatives for change and improvement” (Hart and Bond, 1998:3).



At this point it became clear that that an AR methodology would be best suited to the ontological and epistemological paradigms I had asserted. I therefore looked in more detail at the extent to which AR had been used within the context of healthcare and PPI that I was exploring in my study.

### Action Research in Health and PPI

The use of action research as the methodology of choice is increasing in health related settings (Meyer, 2000b; Morton-Cooper, 2000; Hughes, 2008) and is gaining momentum and credibility in that arena to help address the theory-practice gap where findings from traditional scientific research fail to reflect clinician's own practice (Elliott, 1991; Meyer, 2000b; Morton-Cooper, 2000; Waterman et al., 2001). Nationally, clinicians have been encouraged to carry out research as part of the NHS modernisation agenda (NHS Modernisation Agency, 2001b; NHS Modernisation Board, 2003) and developments in NHS research and development (Department of Health, 2001d).

Coghlan and Casey (NHS Executive, 1996) provide a brief history of nurses, health visitors and midwives in action research, the opportunities and challenges, with a particular emphasis on AR in a hospital facility while Winter and Munn-Giddings (2001) provide examples of AR in a healthcare setting. In a review of AR in the United Kingdom (UK), Waterman et al. (2001), identified 368 studies, of which 59 took place in a healthcare setting and 97% took place between 1988 – 1996. From the 59 studies, eight pivotal factors were identified for future action researchers to consider before commencing AR in their own organisation, including the 'insider' role of the action researcher, managing expectation about concrete changes to practice and the importance of ensuring accurate recording of knowledge and data gained. Waterman's report was criticised for not fully supporting the use of AR and retaining an ambiguity that both followers and sceptics could claim as proving their point (Walsh et al., 2008). It was argued that the difficulty in providing an unequivocal definition of AR may mean that other methods, such as Soft Systems Methodology,

interactive planning and critical heuristics, could be deemed AR but are discounted by Waterman.

There are several examples, like those above, of AR being used within a health setting to explore nursing roles and practices and service user involvement in their own healthcare decision-making (Hart and Bond, 1998; Hampshire et al., 1999; McAndrew and Samociuk, 2003; Day et al., 2009; McKellar et al., 2009). Positive feedback was received from staff in terms of the research acting as a catalyst, raising awareness and providing an opportunity for improvement. Any negative feedback was dominated by the perceived inaccurate data, which failed to match the practice's own data (Hampshire et al., 1999). A systematic review of the uptake of AR in published nursing research concluded that AR is popular within nursing, but the involvement of service users was lacking or at best passive and the focus was usually upon organisational change rather than change to patient care as a result (Munn-Giddings et al., 2008). Researchers using AR in a health setting have reported that AR does not always lead to significant change in the area being explored, but that lessons learned from the process can influence the organisation on a wider level (Meyer, 2000b; Waterman et al., 2001).

Walsh et al., (2008), make it clear that despite a reduction in interest in the use of AR in other areas of research, due to a perceived lack of ability to predict and guarantee a 'valid' outcome, it continues to be relevant for use in health service research. Legislation and policy around patient and public involvement in health is cited as a key driver for the use of AR, as a research method that can embrace the participation of users and practitioners is needed to improve quality of healthcare services. The scientific best practice norm of the traditional style, such as double blind randomized control trials, is not applicable to this study (Morton-Cooper, 2000; Parkin, 2009) and action research is slowly being recognised as a more useful methodology in a healthcare setting.

One GP studied his own clinical practice using AR and noted the methodological challenges he encountered, such as the challenge of balancing being a participating observer needing to retain a certain distance with the need for proximity as an observing participant, concluding that AR produces valuable knowledge that would not have been gained without the self-reflection (Stensland, 2003).

Participatory action research has been identified as empowering patients with early dementia and their families (Nomura et al., 2009) and Portillo et al., (2009) used experimental and professionalizing typologies (Hart and Bond, 1998) through three action research cycles to evaluate a nurse-led social rehabilitation programme for neurological patients and carers. Working with nurses as the AR team, a convenience sample of patient, relatives and nurses were participants. The AR process was used to investigate the results of the evaluation, rather than to bring about organisational change or a change in healthcare.

In a review of AR in healthcare settings Holter et al., (1993) discuss the issue of collaboration, describing a technical collaborative approach, mutual collaborative approach and the enhancement approach from their review of the literature. The authors draw the conclusion that AR is valuable in generating nursing knowledge to improve practice.

The use of action research to explore public involvement itself has been more limited, focusing on how patient and public involvement (PPI) is valued by service users, how people can be supported to enable participation, difficulties in working collaboratively, and the methods and barriers for PPI. (Galvin et al., 1998; Oliver et al., 2000; Truman and Raine, 2002; McElroy et al., 2004; Tutton, 2004). Where changes to service provision as a result of PPI was reported as an outcome, it was claimed that the changes were only able to be put into practice due to access to funds (Pilgrim and Waldron, 1998).

McElroy et al., (2004:10) provide a report on exploring aspects of public involvement in service redesign, using telephone surveys, evaluation of satisfaction from workshops, workshop facilitators' free-style feedback and non-participant observation in a purposive sample of people attending a pre-consultation workshop, then two more main workshops. The researchers claimed to use an action research model in their study, but the report is unclear about the interpretation of this model in their implementation.

In summary, I identified that the methodology that was best suited and remaining from the possible realistic options for my study, was action research. In addition, the paucity of the use of AR in research studies in PPI leaves a gap in its use to better understand the organisational and practitioner context and to facilitate change. This next section, therefore, continues to narrow down and hone my options, this time exploring in more depth the approaches to AR.

### **3.5 Action research models**

Earlier in this chapter I described how there is no one clear definition of AR, however there are key theorists who have described ideologies from pragmatic to emancipatory, developed models to explain the process of implementing AR and provided typologies endeavouring to catalogue the different approaches. These models are explored in turn with a view to identifying a specific methodology for this study.

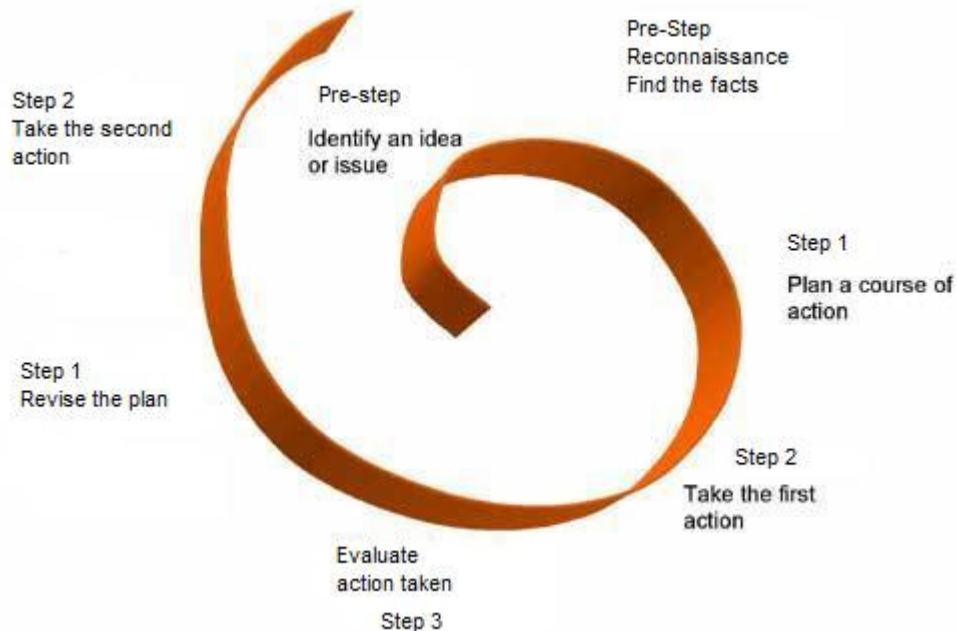
#### **3.5.1 Lewin**

Lewin's (1946) approach involves a spiral of steps within a circle comprising an initial pre-step of formulating a general idea with a desired outcome or objective to reach and fact finding about the current state, followed by a circle of three steps of planning, action and evaluation of the result of the action. At this point, the evaluation feeds into the next cycle, as so it continues (see Table 3.2).

Cycle	Action research stage
Pre-step	Identify a general idea Fact-finding (reconnaissance)
First action research cycle	Step 1: plan course of action Step 2: take action Step 3: evaluate the action
Second action research cycle	Revise the plan of action from what was learned in step 3 Take another action step, and so on through several cycles

**Table 3.2: Lewin’s action research cycle**

This can be shown diagrammatically thus (Figure 3.1):



**Figure 3.1: Lewin's action research cycle (Adapted from Institute for Community Learning, Undated)**

This supports ongoing improvement, validated by collecting and evaluating local data (Lewin, 1966). He claims the action research cycle provides an environment of subjectivity for the participants that enables cooperation and a willingness to reflect openly and honestly on issues to improve a situation and bring about change. Further to the earlier discussion regarding AR methodology, Lewin's ideological approach is one of cooperation between those practitioners affected by the change and the social researcher.

### **3.5.2 Kemmis and McTaggart**

Stephen Kemmis' earlier work (Carr and Kemmis, 1997) draws on the work of Habermas (1973) and his theory of social science that links theory and practice and taking action to overcome social injustice with the aim of emancipation, citing a view of collaborative action research which overcomes "aspects of the existing social order which frustrate rational change" (Carr and Kemmis, 1997:200). This is taken a step further, arguing that what is being described is action research which underpins their definition of AR as "simply a form of self-reflective enquiry undertaken by participants in social situations in which the practices are carried out" (Carr and Kemmis, 1997:162). This work says that AR aims to make improvements in the three areas of practice, the "understanding of practice by its practitioners" and "improvement of the situation in which the practice takes place" (Carr and Kemmis, 1997:165).

Carr and Kemmis (1997:203) describe "practical" AR whereby external facilitators assist practitioners through the AR process of trying out ideas and self-reflection, and explain that their emancipatory action research takes elements of the practical, but with more emphasis on collaboration and participation and a desire to change or improve practice in education and on AR that is "equally concerned with changing individuals" as with "changing the culture of the group" (Kemmis and McTaggart, 1997:16).

In Kemmis' work with McTaggart (Kemmis and McTaggart, 1997:10-11) they describe a variant on Lewin's three basic steps of the cycle of AR within education as; observe, reflect, plan and act, a process of four "moments" of collective self-enquiry where participants collaborate to investigate a shared concern with a view to improving a given situation, for example improving educational practice. Before the process can begin, a thematic concern is identified, which relates to the practitioner's recognition of an issue within his or her own field of practice. This is then shared and discussed with others and agreement is reached on a defined area on which a study will be undertaken. The authors recognise the 'chicken or the egg' dilemma here of needing to identify the concern before putting together the AR team and suggest that the initial collaboration can be as small as the researcher and one other. Similar to Lewin, the authors identify a further pre-step before the spiral of cycles take place, during which a reconnaissance takes place in order to seek a greater understanding of the history and context of what is being studied, for example through a review of the literature on the topic and an analysis of what is going on currently.

They combine the action step with observation and describe how the action should be observed and documented, with action researchers maintaining a journal to record their own observations. They provide an example in a school setting where the 'action' is the teacher (and action researcher) testing out a new way of framing questions to the students and at the same time documenting this by recording what is happening and noting their own observations in a diary.

Kemmis and McTaggart (1997) provide an in-depth, step-by-step 'how to' guide for implementing AR and highlight 17 key points in AR, which include participation and collaboration, as might be expected, but also identify the political process of change and overcoming resistance to change. The authors list several techniques that can be used in AR including interviews, questionnaires, document analysis, recordings, logs and diaries. The action

research team can consists of “those who share a role” or those who “participate together in some activity”, or a blend of both (1997:52).

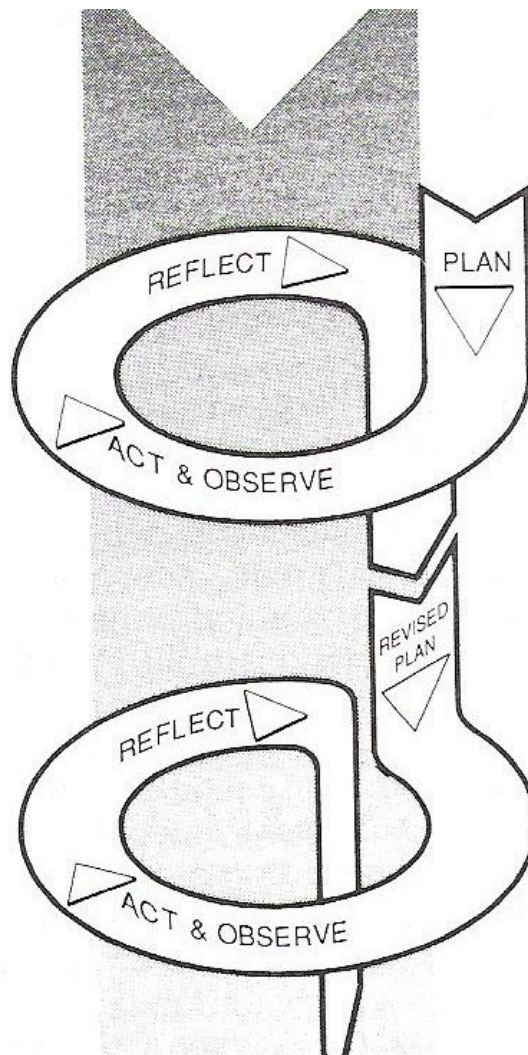
The four steps of this model are as follows:

1. **Plan** – forward looking and critically informed in the sense that the participants understand the social and political constraints within which they are working and in being empowered to approach the topic in a more scholarly, systematic and rigorous fashion. This part of the AR cycle provides a clear rationale for the next “moment” and the plan for action and is derived.
2. **Act** – critically informed action that has an educational intent and is flexible and adaptable to unforeseen circumstances, as it takes place in the real world.
3. **Observe** – a process of documenting the action and maintaining journals to record personal observations.
4. **Reflect** – comprising of group reflection and discourse, using the documentation and observation to help plan the next action.

(Kemmis and McTaggart, 1997)

Diagrammatically, the model can be seen in figure 3.2



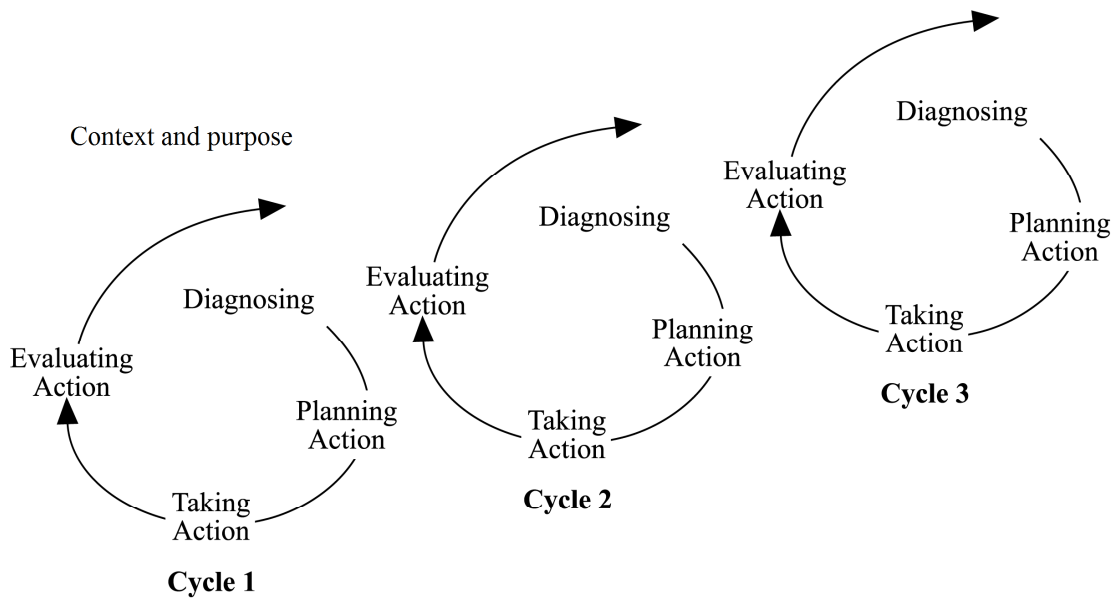


**Figure 3.2: Kemmis and McTaggart's action research cycle.** (Kemmis and McTaggart, 1997:11)

### 3.5.3 Coghlan and Brannick

Coghlan and Brannick (2003) offer another perspective on Lewin's traditional AR cycle (see Figure 3.3) by providing more explanation of the of the pre-step of the AR, defining the context and purpose element and separating out a 'diagnosis' from the pre-step into the first step of the AR cycle. They also incorporate Lewin's (1997) 'Force Field Analysis' work by considering the driving and restraining forces, both in socio-economic and political terms, and

determining the new ‘desired state’ before embarking on a new first step of the cycle.



**Figure 3.3: Coghlan and Brannick’s action research cycle** (adapted (2003:19))

Coghlan and Brannick (2003:8-9) state that irrespective of the confusing collection of AR ideologies and approaches there are three common features to all:

1. it is participatory in that “research subjects are themselves researchers or in a democratic partnership with the researcher”;
2. the process acts as a an agent of change; and
3. data and evidence is “systematically collected and come from the experience of the research participants” using a range of methods and techniques.

While some theorists (Kemmis and McTaggart, 1997) argue that taking each step of the cycle is critical, a strong body of research claim that following

clearly delineated step-by-step processes in an action research study is challenging and that it is more likely that the researcher will have a more muddled or meandering path (Morton-Cooper, 2000).

Carr and Kemmis (1997) suggest it is possible that a critical interpretative approach would allow practitioners to perceive their own actions in a different way and potentially change their own practice. To be valid, the participants must agree with the interpretation. Conversely, interpretations can also be criticised, as these, too, are linked to values and beliefs and therefore any new interpretation of their actions may be met with emotional resistance to change.

Elliott (1991:70) also revises Lewin's model and allows for ideas to "shift", with constant analysis of findings at all stages and the need to monitor the extent to which the action has been implemented.

Wisker (2001:159) focuses her definition of AR on academics and education and describes it as "practical, participative, emancipatory, interpretative and critical".

The confusion of definitions for AR has also led to a need to determine the different types (typology) of AR to enable its application to different situations and problems. Hart and Bond (1998) therefore suggest that AR can be broken down into seven interactive types of criteria to help establish the type of AR required (see Appendix 1) claim that by analysing these seven criteria it can be established where on the scale of four distinguishing types of AR the work will sit: experimental, organizational, professionalizing or empowering. Critics argue that although it is useful to have this typology, in reality AR does not always follow these classifications (Meyer, 2000b). Hart and Bond (1998) themselves recognise that over the period of time of an AR project, the different cycles can shift to different typologies and that their typologies should be considered as a way of trying to 'make sense' of AR rather than a rigid set of rules.

To summarise, this section has considered AR in more detail, exploring the various models, ideologies and typologies with which researchers and theorists have endeavoured to classify and explain their frameworks and processes. In this next section, I identify my approach to this AR study.

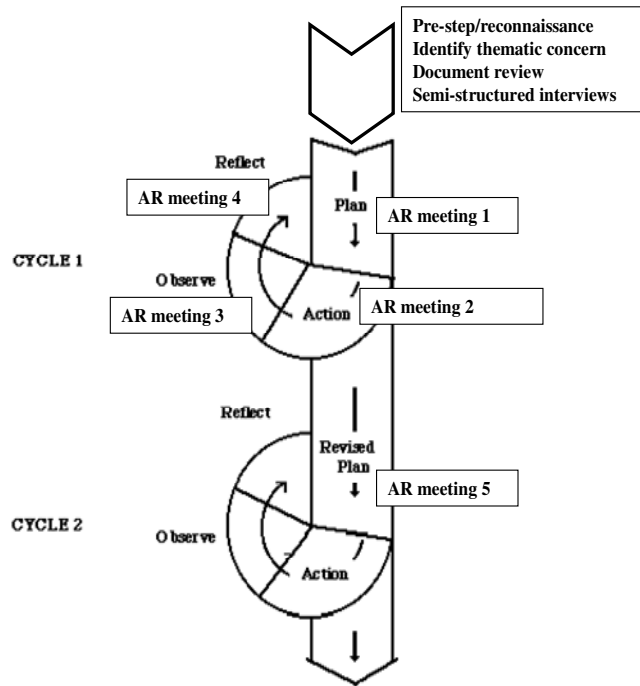
### **3.6 My AR framework**

Many authors and researchers have offered guides on how to carry out AR in an organisation (Kemmis and McTaggart, 1997; Hart and Bond, 1998; Hampshire et al., 1999; Coghlan and Casey, 2001; McNiff et al., 2003) and within the literature there is some discussion regarding the perspective of the AR project in terms of the focus of the research. Should it be in relation to the researcher changing their own work practice in a ‘how do I...?’ framework (McNiff et al., 2003), is it about providing facilitation to enable colleagues to change their work practice, or about the organisation as a whole changing their culture and way of working? Reason and Marshall (1987) argue that AR is ultimately for all three audiences; for ‘me’, in terms of changing one’s own work practice; for ‘us’, in terms of a team struggling with a problem; and for ‘them’ in terms of useful knowledge that can be transferable more widely.

This last approach is one that had resonance for my own study and practice and draws together the organizational and professionalizing typologies to which I referred earlier. The AR study was to improve my understanding of what would enable an organisation to provide outcomes to PPI inputs and enable me to achieve my academic goal. At the same time, the healthcare practitioners struggled with finding the time to do PPI and, as will be shown in the findings, failed to follow through to change in practice. Finally, the ‘them’ here is other practitioners in the field of PPI and, as will be shown, a change in national policy guidance as a result.

The intention for the method was to take a practical and pragmatic approach and broadly follow Kemmis and Taggart's (1997) cycle of steps or moments by having a series of meetings simply called 'plan', 'act', 'observe' and 'reflect' and then begin the second cycle with one further 'plan' meeting. I separated the action from observation, as the actions would be carried out by the AR team clinicians, excluding myself as a non-clinician, and the next meeting would allow us to discuss their observations and any documentation. I would then leave the AR team to carry on, if they so wished, outside of this study. This cycle would incorporate a pre-step of fact finding and reconnaissance to identify the thematic concern, as originally suggested by Lewin (1946) and expanded by Kemmis and Taggart (1997).

The intended AR process is shown in Figure 3.4



**Figure 3.4: Intended AR process** (Turner after Kemmis and McTaggart, 1997)

In table form, this can be seen as:

Cycle	Action research stage
Pre-step	Identify a general idea Fact-finding (reconnaissance): Document review Semi-structured interviews
Cycle 1	AR Team meetings: Plan Act Observe Reflect
Cycle 2	Revised plan

**Table 3.3: Intended AR process**

The AR pre-step of having both a general idea, or thematic concern, and insight, or reconnaissance, into the context within which the research will take place, sits well with academic research such as this, where I needed to consider why the study was necessary or desirable.

Using Hart and Bond's typology (1998) I anticipated that the AR process would follow a more experimental typology, with a problem to be solved in terms of my research aims; it was time limited with strictly delineated cycles. This appealed to me in that it appeared to be a structured technique and the collaboration was limited to almost an experimental level.

However, as my understanding of action research developed through my reading, my stance became somewhere between organizational and professionalizing. The question that needed answering was about improving my own practice, and that of my fellow practitioners, thereby potentially making improvements on behalf of patients and service users. It was not directly about empowering patients or practitioners, nor was it emancipatory. However, nationally there is legislation and guidance that calls for evidence of change resulting from PPI, therefore my research could be deemed top-down, directed towards achieving managerial aims. In addition, there was to be a selected membership, in terms of the sample for the semi-structured interviews and in choosing the group of healthcare practitioners from which to draw volunteers. I defined the problem from my own practice, though it could be argued that other practitioners in the same field of PPI management, if not the participants in my AR study, had identified the problem as a professional group, as described in Chapter 2.

Again, using Hart and Bond's typology, the degree of collaboration in my action research also needs to be identified. I saw myself as the expert insider researcher and the staff members were participants, not co-researchers. Participants were not strictly co-change agents, although it is shown in the

analysis that they were able to bring about change within their own practice as a direct result of the action research.

### **3.7 Chapter summary**

In this chapter, I have outlined my ontological and epistemological approach to this study. That in turn guided my choice of research methodology. I then continued to hone my options, discarding or accepting, to choose an action research methodology and a pragmatic approach to Kemmis and McTaggart's (1997) cyclical framework. Having outlined the overall framework of the study, the next chapter describes how I intended to implement the research.



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## CHAPTER 4: RESEARCH METHOD

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### 4.1 Introduction

Having described and justified the research methodology, this section of the thesis explains how it was intended to apply it in practice. Firstly, the site for the research is identified, followed by an explanation, timeline and diagrammatic description of the method to be applied. The phases of the action research pre-step and cycles and methods of data collection are then explained, starting with identifying the thematic concern, next the document review and then semi-structured interviews followed by the process of the AR team meetings. Finally, the rigour of the study is clearly expressed and the ethical considerations are detailed.

### 4.2 Where the research was conducted

PCTs were highlighted as having a crucial leadership role in changing services to improve the patient experience (Healthcare Commission, 2005a) and the views of patients who use services were vital when the Healthcare Commission inspects PCTs to rate their performance and award their 'star ratings' (Felton and Stickley, 2004:96). It was therefore appropriate to use a PCT as a site for the research.

WNPCT, my employing organisation at the time, was used as the research site and Chapter 5 provides information about the size of the population, budget and infrastructure. It will be shown that the action research site, although only a single PCT, represented something of a critical locus for the research questions described earlier since it was a lead for patient and public involvement (PPI) on many levels. It was a site that viewed itself as fairly innovative in the area of

patient and public involvement, though the extent to which PPI has been implemented across the Trust had not been evaluated.

WNPCT was seen as a leader in the field of PPI (Department of Health, 2006d), as can be demonstrated by my involvement in helping to write the national PPI guidance (Department of Health, 2003d, 2003e), and the use of the PCT as a DH case study site for good practice and sharing the learning with other Trusts (Turner, 2001e) and the awards it has received in recognition of its work in PPI (Institute of Public Policy Research (IPPR), 2002). This is further described in the document review in Chapter 5.

The PCT had also been cited in national publications where viewpoints from experienced practitioners were sought (Stevenson et al., 2000). In addition, over 40 PCTs and NHS Trusts across the country and abroad approached WNPCT over the years for guidance, information and support in completing their own strategies, planning and implementing PPI; see Allen (2001), Child (2001), White (2002), Wilkinson (2002), Gibbs (2003) and Clifton (2004).

This could all suggest that WNPCT was atypical and therefore there would be implications for transferability of results, however it is later shown in the document review that, despite WNPCT being a leader in the field of PPI *activity*, there was still evidence of a ‘brick wall’ in line with other PCTs across the country. Researchers have argued that “in order to develop more generalizable conclusions, it would be necessary to interview a larger sample taken from a variety of different sites” (Stevenson et al., 2000). However, WNPCT was not atypical in terms of its organisational structure and services and it was anticipated that the findings from this research could be transferred and also make a contribution to understanding in general terms. Qualitative research is often criticised for not being generalisable, however it focuses on “drawing inferences from one setting to another” (Williamson et al., 2004). It is further argued that the small size of the sample is not a consideration in action research as similar institutions would be interested in the findings (Perry,

2001) and this therefore addresses the issues of transferability, as described later in the section on rigour.

Having justified the use of WNPCT as the site for this study, I now provide an overview of the intended AR process.

### 4.3 Action research pre-step

Further to the discussion in Chapter 3, Lewin (1946) described a fact finding reconnaissance task in the action research cycle of determining the baseline of thinking amongst community workers, what their usual actions are and what barriers they come across. Kemmis and McTaggart (1997) agreed with the need for reconnaissance and an investigation into what is currently happening.

The thematic concern and general objective for this study discussed in Chapter 2 and 3 can be illustrated thus:

<b>Thematic concern</b>	Patient and public involvement activity is not influencing healthcare planning and decision-making
<b>General objective</b>	To indentify the enablers and attributes that would enable PPI to influence healthcare planning and decision-making

**Table 4.1: Thematic concern**

There is a range of methods that can be applied to gather data in a qualitative research study; including interviews, focus groups, participant observation and diaries. Given my familiarity with particular methods of data collection during my working life, I chose three different data collection tools, collectively forming the action research pre-step; firstly, a document review and secondly semi-structured interviews. Thirdly, the critical literature review in Chapter 2

could also be considered part of the pre-step in that it provides a reconnaissance of the national context to PPI, describes the drivers and forces for change (Coghlan and Brannick, 2003) and identifies the issues (Lewin, 1946) and thematic concern (Kemmis and McTaggart, 1997) .

#### 4.3.1 Document review

An organisational document review offers “partial insights into past managerial decisions and actions,” although the public documents do not necessarily accurately reflect “how different organisational actors perceive the situations in which they are involved” (Bryman and Bell, 2003:413-414), nor are they objective accounts (Green and Thorogood, 2004). Establishing fact or bias is a key aim of a document review (Bell, 2002) and, combined with the semi-structured interviews (see 4.3.2), I had the opportunity to explore this issue further and investigate any divergence, distortion or bias.

It was also intended that the data collected would provide a history and context for the research and form another element of the action research pre-step. This would involve the critical examination of existing records or documents, the data from which would supplement the data obtained from the semi-structured interviews and assist identification of a service or team to participate in the third method; the Action Research Team. The documents forming this review would include formal policy and strategy statements, public literature, Board papers, personnel documents and PPI activity reports. The documents would be used as resources in order to review what they “denote about the world” of PPI in the PCT (Scott, 1990:36).

The document review would also help with the research questions as it would give an indication of the extent to which national PPI policy had been interpreted into local policy, providing another source of data to help

triangulate the semi-structured interviews and the action research. By investigating the reports of any PPI it is also possible to explore (a) the management executive's collectively stated values and beliefs around PPI and (b) the stated changes or improvements to patient care as a result of PPI activity.

I intended to use four criteria for assessing the quality of the documents I would review (Scott, 1990:6):

1. Authenticity – genuine and of unquestionable origin
2. Credibility – free from error and distortion
3. Representativeness – typical of its kind
4. Meaning – clear and comprehensible

In this study, my organisational role was pan-organisation therefore I had primary access to documents, with my own extensive personal library of WNPCT documents and with unlimited access to the organisation's archive library. To carry out the document review, I intended to use similar search terms and key words to those used in the literature review of Chapter 2; 'public involvement', 'patient and public involvement', 'patient involvement', 'user involvement'. There was no need to add any Boolean indicators, such as 'health', as the documents were all health-related.

#### 4.3.2 **Semi-structured interviews**

I wished to ask questions of a range of staff in the organisation to gain insight into their broad understanding of PPI, how much had filtered through from any local implementation of the national policy, and then investigate what value or importance participants placed on PPI in their own sphere of work (see Chapter 3). I was familiar with using both questionnaires and interviews to obtain data

from patients and the public and these were therefore the two practical choices I considered.

Questionnaires can be used to measure attitudes and behaviour (May, 1997) and it is advantageous in that it is often a cheaper option than the hours of interviewing and transcribing and provides more anonymity of participant (Kumar, 2005). However, there are also several disadvantages which include the potential for a low response rate, questions following the direction of the researcher's interest (Davies, 2007), potential confusion for participants due to the lack of clarity around the questions and a lack of depth and richness to the answers (Kumar, 2005). In addition, questionnaires are based on a positivist approach, with the emphasis on removing researcher bias (May, 1997). Further to my discussion in Chapter 3, I was not able to distance myself from my study, which means I could inadvertently bias the questions towards my own beliefs and experience of PPI, thereby negating the removal of researcher bias. On these grounds, the use of questionnaires was rejected.

To gain insight into the attitudes, beliefs and experiences of staff, interviews are recognised as a valuable method (May, 1997). Schwandt (1997:75) defines interviews as “a form of discourse between two or more speakers”. Kvale (1996:71) offers a ‘how to’ guide for the entire qualitative research interview project, defining interviews as an inter-change of views on a topic of mutual interest – a “professional conversation.” In contrast to questionnaires, interviews allow for richer data collection and allows for further clarification and probing (Kumar, 2005).

Three basic types of interviewing individuals used in qualitative research are structured, unstructured and semi-structured (May, 1997; Green and Thorogood, 2004; King, 2006) and I needed to make a choice regarding the type of interview that would be most appropriate for my study and would best suit my methodological approach.

With structured interviews, it is expected that every participant is asked the same question, which allows comparability. The researcher has a neutral and non-subjective role, and participants follow the interest of the researcher (May, 1997). Here, there is the potential for a similar problem to that identified above, whereby my questions could pre-judge responses based on my a priori assumptions and the participant, by the nature of the structured interview, would have limited opportunity to diverge from those assumptions. I therefore rejected this approach.

Unstructured interviews allow the greatest flexibility for participants as the researcher follows the interest of the participant, using a set of prompts, however the disadvantage is the time required to collect, transcribe and code the interviews (Kane, 1997).

Semi-structured interviews provide the researcher with the framework to ask a set list of questions to allow comparability (May, 1997), whilst at the same time allowing flexibility. With this structure, the questions are “open ended, and there is more emphasis on the interviewee elaborating points of interest” (Denscombe, 1998:113) and the participant “determines the kind of information produced” (Green and Thorogood, 2004:80). This is a method of interviewing with which I was very familiar, having used semi-structured interviews, and taught others to use them, in my work as PIM to glean ‘patient stories’ as part of PPI. In addition, participants would be familiar with the method and therefore accept it more readily (May, 1997; King, 2006).

Kvale (1996:88) disputes the idea that qualitative research interviews lack objectivity, calling them “inter-subjective interaction” and arguing that this very subjectivity is their strength, allowing a delving of understanding to find “hidden meanings” behind people’s views and experiences and the choices people make.

Kvale (1996) advocates methodological preparation for the interview process and identifies several stages of a research interview: thematizing; designing; interviewing; transcribing; analyzing and identifying. He talks of briefing and debriefing the interviewee to clarify any questions the participant may have and advocates active listening. Interviews are time consuming and it is recommended that each one last approximately one hour, following a sequence of introduction, “warm-up, main body of interview, cool-off and closure” (Bell, 2002; Mathers *et al.*, 2002).

Interviewers require good listening skills and the ability to build a rapport and probe for information. A good interviewing technique is one where the interviewer avoids making judgemental statements and apportioning blame in response to participants, but instead creates a rapport and empathy with the interviewee, asking clarifying questions and being attentive (Partington, 2001). All of these were skills I had honed through my journalistic career and my role as PIM.

### Study sample

Chief Executives, Professional Executive Committee members and PPI leads have been participants in public involvement research, as have patients, however “those who conduct research on workers rarely get round to investigating managers, and vice versa” (Wisker, 2001:139), hence the sample for the pre-step interviews would comprise firstly of a quota sample of both managers and workers. At the commencement of the field work in 2005 there were 777 members of staff employed by WNPCT, delineated by their contracts into seven staff groups plus heads and directors of service.

A quota sample of the layer of Heads and Directors of Service was chosen as it has been argued extensively that there needs to be commitment to public involvement at the top of the organisation if it is to be effective (Wisker, 2001) (see Chapter 2). I planned to send out these invitations. This was also a



purposive sample; as Heads and Directors of service they were considered to be 'key informants', with particular knowledge of the subject being addressed and having decision-making roles and responsibilities for cascading ethos and practice. As was highlighted in the document review (see Chapter 5), the Heads and Directors of Service worked directly with the Public Involvement Manager and had therefore been subjected to more promotion and awareness raising literature, documentation and communications regarding public involvement. There was an expectation that they would have been tasked with 'cascading' both the information and the directive to staff within their teams to carry out public involvement activity. The interviews of those staff had the potential to reveal any shortfalls in this process/assumption.

A purposive sample of two was to be selected from each of the strata to ensure a mix of staff from across the organisation and within each staff group. Two members of staff from each of the professional groupings were chosen in order to "get a fair spread and to reduce bias of choice" (National Consumer Council (NCC), 2002a). Within West Norfolk PCT, only the human resources department had access to information regarding staff groups, as the information was considered confidential. The selection for the study would be made by the PCT's Head of Human Resources and Organisational Development as the HR administrators (who were not employed by the PCT and therefore outside the remit of this study) felt unable to assist due to other priorities and commitments.

The HR department lead would distribute these invitations and she would attempt to obtain a sample that to her seemed representative of the population with a good mix of 'junior' and 'senior' staff within each staff group. Only upon receipt of the returned consent forms would I be notified of the names of the participants were and, to my knowledge, nobody refused to participate, as all 25 forms were returned. It is argued that "most qualitative research" is purposive, in that it is "explicitly selecting interviewees who it is intended will generate appropriate data" (Green and Thorogood, 2004:102). The purposive

sampling of the staff groups was justified here in that the study was concerned more with obtaining an idea of the *range* of responses rather than the *proportion* of the population giving a particular response.

25 members of staff were involved in the overall sample for interviews ( $n = 25$ ).

<b>Sample and population* for semi-structured interviews</b>		
<b>Staff Group</b>	<b>Population</b>	<b>Sample</b>
Heads and directors of service	11	11
Medical and dental	32	2
Nurses and midwives	435	2
Allied health professionals	55	2
Health scientists	67	2
Senior managers	48	2
Administration and clerical including estates and facilities	129	2
<b>Total</b>	<b>777</b>	<b>25</b>

(\*as at 1 October 2004)

**Table 4.2: Sample and population for semi-structured interviews**

### Interview questions

Guiding thematic questions were developed to reflect the key areas of interest – the meanings and understanding of public involvement, commitment to implementing public involvement and the barriers and opportunities. I

intended to test these guiding interview questions on lay members of a PPI in Research panel and then further refine them by conducting a preliminary pilot interview to test the flow and rationality of the questions. The pilot interviewees would be colleagues who had worked with me in the field of PPI but who would not be participants in the final study.

The semi-structured interviews would commence with a 'checklist' of issues that I wished to address. I would guide the discussion to cover the topics on the checklist, whilst leaving room to pursue any relevant subjects that are brought up by the interviewee (Wisker, 2001:138). Kvale (1996) identifies nine types of interview question from introducing and probing types of question to interpreting and structuring questions and the use of silence (Robson, 2003:277), arguing that the 'why and what' questions should be dealt with before the 'how'. In this study, participants would first be asked what they knew about PPI in its wider sense (e.g. national and local policy), what experiences they had of PPI and then why they had certain beliefs or values. They would then be asked 'how' questions, for example, how PPI might be improved and how barriers might be overcome.

The same questions would be asked of each interviewee (see Appendix 4) thereby allowing comparison of responses, but also the opportunity to ask open-ended questions to get richer data (2002). Those staff selected would then be invited to participate and given information about the research. Informed consent is vital and all participants would be asked to complete a participant consent form (see Appendix 3).

All interviews were to be digitally recorded and transcribed with the consent of the interviewee. I would transcribe the interviews and then verify the transcripts against the digital recordings to check for accuracy in transcription and to reacquaint myself with the interview and the discussion. It is argued that transcribing is not a neutral activity (Kvale, 1996) and that the researcher should ensure rigour of transcription, recognising that a transcriber has the

potential to introduce their own bias and prejudice (Lapadat and Lindsay, 1999). It is also open to errors in accuracy and differences in the levels or recording, for example, whether or not to include the occasional 'um' or 'er' (Miles and Huberman, 1994). However, I intended to type everything verbatim, minus the 'ums' and 'ers'. I would also play back each digital recording whilst reading the transcripts several times, to ensure that I had understood the nuances of the conversation. In addition, interviewees would be given the opportunity to ratify or amend their interview transcripts, should they wish to, also reducing the potential for bias on the part of the transcriber.

I intended to conduct the interviews during the autumn and winter of 2005 in a suitable venue mutually agreed by the employee and me and each interview was expected to last circa 60 to 90 minutes. Green and Thorogood (2004:95) suggest it is "easier to interview in a private space that the interviewee feels is 'theirs,'" therefore participants would be asked where they would like to be interviewed and I intended to make every effort to accommodate their choice, providing there was privacy.

The intention was to introduce the context with a briefing prior to the interview, with me defining the situation for the subject, i.e., the purpose of the interview, use of recording equipment and allowing any questions from the participant as they arise. The debriefing would take place after the interview once the digital recorder was off.

I intended to use both open and probing questions. The use of open questions was to encourage full responses from interviewees, e.g. "what have been your experiences of public involvement within WNPCT". Probing questions were employed to delve further into the experiences of the interviewee to pursue specific issues, e.g. "Where does public involvement fit into your work priorities?" The interviews were transcribed verbatim.

To help reduce any perceived researcher bias, participants would be asked to corroborate the initial data by being given the transcripts from the interview to amend if necessary. Only then would the data to be used. Bell (Stevenson et al., 2000:321) argues that this is a necessary part of verifying interview data.

#### **4.4 Recruitment to the AR team**

I had three pragmatic options in terms of choosing participants to form an Action Research team following transcription and analysis of the interview data and the document review:

- 1) Where a team had no experience or shown no interest in PPI prior to the research. This option would have provided the opportunity to see a piece of PPI activity through from start to finish and observe along the way the enabling or disabling factors. However, the PCT was going through a period of major reconfiguration which brought with it time constraints (the staff, myself included, may no longer be employed by the participating PCT) making this option unviable.
- 2) Where PPI activity had been carried out and the outputs of such had led to change in service delivery. This option would have allowed a focus on what enabled the PPI activity to lead to an outcome. However, the drawback would be that the time would already have passed and participants may not have remembered what the enabling factors were.
- 3) Where PPI activity had taken place within a service or team but there had been little or no outcome in terms of change in service delivery or care. This option would enable the researcher and the participants to explore why this situation had occurred and use the action research process to identify, plan and test small changes which in turn would provide some key data for the attributes and enablers for effective PPI.

Having considered the above options for taking this study forward, Option 3 was chosen. Here would be examples of patient and public involvement activity that had not led to change, exemplifying the 'brick wall' between PPI activity and change to healthcare services as a result. By choosing this option, there was the opportunity to explore, in real time, exactly what would enable the change. The decision was also based on pragmatism in that time was limited due to the pending reconfiguration of PCTs. My own job within WNPCT was about to become 'at risk' and by October 2006 I may no longer have had a public involvement manager position or, indeed, be employed by the new PCT. This could have restricted my access to staff and may have affected the affordability of the doctorate, which was then being funded by WNPCT. In addition, service provision staff would be transferring to the new organisation and the new PCT may not have wished PPI activity to be undertaken and/or the staff may have been unwilling to invest the time whilst adapting to a new employer. Option 3 was the compromise of still enabling the team to work together to establish the attributes and enablers, whilst potentially providing tighter timescales. The AR team itself would determine the activity.

I did not consult others in this decision, as at this stage it still felt very much my research for my PhD rather than a participative study. However, the practical restraints were such that the time left in which to carry out the AR meetings were restricted, if they were to continue within the auspices of West Norfolk PCT. Any delay would result in the need to seek approval for the study in the new organisation and reapply for ethical approval.

## **4.5 AR Team reflection diaries**

I was very aware of the potential impact of my insiderness on participants in terms of being the Public Involvement Manager involved in the very work the AR team would be examining. I was concerned about how I might inadvertently direct them to my way of thinking or prevent them from speaking freely. Equally, they may not all feel comfortable to speak out in a group, and

this had been my experience over the years, where some participants had a more reflective style than others. I wanted to be able to capture any thoughts and insights that occurred to individual participants after and in between meetings, rather than just the group perspective. I was aware that some participants may express themselves more readily in writing. The use of participant diaries can be advantageous here in gathering individual perspectives, providing some detachment from my influence and allowing more data from yet another source (Cassell and Symon, 1994; Easterby-Smith et al., 2002).

Reflection upon learning is an integral facet of action research (Elliott, 1991; McNiff, 2002; McNiff et al., 2003), so at the first AR meeting, I intended to ask members of the action research team to keep a 'reflection diary' in which they reflected on their feelings in relation to the research project and made practice observations between meetings. Participants would be given the choice on whether or not to keep the diary, when to fill it in or not, and when or if to share it and how (e.g. read out in the group or give to me to read outside of the meeting). If they felt comfortable they would share their reflections with the group, with me only, or not keep the diaries at all, if they preferred. The intention was to use the diaries as further data to explore the attitudes and beliefs of the participants when they had time to reflect on the action research process, the project or their own actions and practice. I would also keep a reflection diary, separate to my overall reflexive journal that I maintained throughout my doctoral study. Any data shared from the diaries would be included in the overall analysis of the data from the meetings, rather than analysed as a separate method.

## 4.6 Data collection and analysis

“Data analysis is the process of bringing order, structure and meaning to the mass of collected data” (McDonnell et al., 1999; Stevenson et al., 2000) and I would theme the qualitative data from the interviews in a systematic and coherent way (Marshall and Rossman, 1995). Implications for policy or practice may also be derived from the data. The procedure I intended to use for analysis had five modes (Robson, 2003):

i. Organising the data

Theming had already begun when developing the question topics, as discussed above, performing a task of “anticipatory data reduction” (Miles and Huberman, 1994:10). The transcripts of the digital recordings would then be read several times to enable me, the researcher, to become ‘familiar’ with the content and the emerging issues. I would then organise the data by drawing up charts in which the questions were shown alongside the participant, linking key passages of the transcripts and paraphrases to the relevant question.

ii. Generating categories, themes and patterns

The organisation of data above would enable an initial overview of the responses to each question theme, providing initial categories and patterns.

iii. Testing the emergent hypotheses against the data

These themes would be a literal interpretation of the answers to the questions, rather than an analysis of what was being said and why. A further sifting and sorting of the key phrases would take place to seek new relationships, themes and variables.

iv. Searching for alternative explanations for the data

Following the further sifting of the data, a further distillation provided a new rationalisation of the findings.



v. Writing the report

The subsequent report would be written into this thesis.

## **4.7 Rigour**

The importance of establishing rigour in qualitative research has been highlighted (Lincoln and Guba, 1985; Guba and Lincoln, 1989; Mays and Pope, 2000). There is significant discourse on the topic spanning over 20 years, debating the terminology, definitions, criteria and the sense of the words used, with no unified conclusion drawn (Sandelowski, 1986; Miles and Huberman, 1994; Waterman et al., 2001; Hope and Waterman, 2003; Tobin and Begley, 2004; Rolfe, 2006). The traditional scientific, positivistic criteria for establishing rigour of validity, generalisability, reliability and objectivity have been disputed and redefined as trustworthiness and rigour, then the original criteria re-emerged following arguments that by not using traditional terms this would somehow make any qualitative research appear ‘sloppy’ (Guba and Lincoln, 1989; Davies and Dodd, 2002; Golafshani, 2003). In some cases ‘validity’ is used as the homogeneous term for overall rigour (Sandelowski, 1986; Cresswell and Miller, 2000). In addition, debate had taken place regarding the identification of criteria against which to establish rigour in action research (Waterman, 1998; Hope and Waterman, 2003). Furthermore, it has been claimed that it is impossible to have an agreed set of criteria for qualitative research, as the very nature of qualitative research itself is still being challenged (Rolfe, 2006).

Guba and Lincoln (1989) recommend four criteria against which to assess rigour, as seen in table 4.3, although they express some dissatisfaction with the use of these criteria as they are parallel to those used in a positivist methodology upon which, they argue, there is too much emphasis on the significance of method.

<b>Constructivist</b>	<b>Positivist</b>
Credibility	Validity
Transferability	Generalizability
Dependability	Reliability
Confirmability	Objectivity

**Table 4.3: Rigour criteria** (Guba and Lincoln, 1989)

Kumar (2005:153) suggests the pertinent questions to establish rigour are “is the research investigation providing answers to the research question for which it was undertaken and, if so, is it providing these answers using appropriate methods and procedures?” It has also been suggested that the viewpoint (“lens”) and “paradigm assumptions” of the researcher that dictate how rigour is established and will vary dependent on the nature of the study:

<b>Paradigm assumption/lens</b>	<b>Positivist or systematic paradigm</b>	<b>Constructivist paradigm</b>	<b>Critical paradigm</b>
Lens of the researcher	Triangulation	Disconfirming evidence	Researcher reflectivity
Lens of study participants	Member checking	Prolonged engagement in the field	Collaboration
Lens of people external to the study (reviewers, readers)	The audit trail	Thick, rich description	Peer debriefing

**Table 4.4: Validity procedures within qualitative lens and paradigm assumptions** (Cresswell and Miller, 2000:126).

Coghlan and Brannick (2003) suggest that rigour in AR is provided by showing how the process of cyclical steps was implemented and recorded, reflexivity for transparency of the researcher's bias, the use of both confirming and contradictory views of participants and the grounding of interpretations in theory. They summarise that a good AR project clearly explains "what happened", how the researcher "made sense of what happened" and "so what" (Coghlan and Brannick, 2003:24). McNiff et al., (2003) provide five forms of validation for AR that cover issues around self-determining that one did what one set out to do, demonstrating to others that you have identified improvements in practice and that you acted in the best interests of stakeholders (e.g. patients). In addition, it is claimed that the action research process itself provides a form of validation, both morally, by attempting to improve practice and reflexively, by considering and being transparent about any personal bias (Waterman, 1998).

It is within this somewhat challenging but significant context that I needed to determine appropriate criteria against which to judge the quality, and evidence the rigour, of my own qualitative action research study. There is an argument that the use of parallel terminology somehow relegates and diminishes qualitative research and, furthermore, that it "actually undermines the issue of rigour" (Morse et al., 2002:8). Borda (2009:33) claims that "common sense" should direct the identification of criteria, whilst Miles and Huberman (1994) marry the traditional positivist terms with more alternative constructivist terms to cover both arguments and Sparkes (2001) argues that it is likely that the disagreement and controversy will continue and that there will be no one set of correct criteria to which researcher should adhere. With no conclusive set of criteria against which to establish the rigour of my study, I have chosen to use a blend of traditional and constructivist criteria and it is against the two parallel sets of criteria that I judge this study.

### 4.7.1 Credibility/validity

Kumar (2005:159) defines validity as “the ability of an instrument to measure what it is designed to measure” whilst Miles and Huberman (1994) suggest that both credibility and validity can be established by ensuring that the findings of the study make sense, identifying convergence or explanation of conclusions from triangulation, seeking negative evidence and identifying areas of uncertainty.

Guba and Lincoln (1989) provide five techniques for evaluating credibility:

- Prolonged involvement
- Persistent observation
- Peer briefing
- Negative case analysis
- Progressive subjectivity
- Member checks

Taking each of these subdivisions in turn, starting with prolonged involvement, at the time of the study I had been involved in the field for several years, providing an a priori understanding of the constructions built around patient and public involvement. The semi-structured interviews allowed me to explore and understand this more in depth, testing both my assumptions and providing rich data on understanding, perceptions, value, culture and experience of the participants. Advantage is gained from an insider researcher being aware of both the ‘public life’ of the organisation (the strategies, vision and Board reports) and the ‘private life’, for example the culture and internal politics (Coghlan and Brannick, 2003) and experience ease of implementation and insight into the project (Robson, 2003). Disadvantages include lack of time, expertise and confidence in research and an existence of preconceptions (Robson, 2003).

Being an insider researcher can have implications for the level of access to the organisation to gain sufficient depth of understanding. Two levels are discussed; primary access (the initial access into the organisation) and secondary access (to specific parts of the organisation) (Coghlan and Brannick, 2003). It is suggested that although insider researchers have an advantage in terms of access, this can be a disadvantage, as it may mean the researcher's seniority excludes participation in informal networks.

Persistent observation was undertaken by using a range of methods to elicit the most pertinent data. Triangulation is identified as one of the techniques to improve credibility, using different data collection methods, such as questionnaires, interviews, observation; different sources of data looking for any pattern or congruence. Through using more than one method, the weakness of one can be offset against the strengths of another, challenge the bias of one method and “fill the gaps” (Green and Thorogood, 2004:208). For the purposes of the study, triangulation was provided via semi-structured interview process which allowed participants to indicate what they felt to be the most important around the topics we were discussing, a document review, reflective diaries and an AR team. Further to the discussion at the beginning of this chapter, however, my own ‘world view’ “may exert a strong influence on what is seen as important” in the research (Bell, 2002) and therefore my chapter on reflexivity provides perspective on how this may have occurred.

During the period of this study I shared the findings with my peers at the Department of Health, the Strategic Health Authority and within my own work colleagues a part of a peer briefing. The Department of Health incorporated my findings and recommendations into the drafting of the revised legislation guidance, ‘Real Involvement’ (DH Commissioning and System Management - PPE, 2008). In addition, I shared the work at Strategic Health Authority level, providing a check that my findings resonated with other PPI managers. Similarly, I presented my findings with my own patient and public engagement team in NHS Norfolk. One member of staff who had also been employed in

one of the pre-reconfiguration PCTs agreed that the findings struck a chord with her, while all of them recognised that the outputs from the research had already been put into strategies and staff objectives locally.

Negative case analysis involves the identification of findings that contradict the majority, thereby providing assurance of a depth of study. As will be seen in Chapters 5 and 6, attention was given to those findings that disagreed with the most commonly held views, thereby providing the assurance required that the study undertaken was comprehensive and prepared to look beyond the obvious themes.

Throughout my doctoral study I maintained a reflexive journal, where I recorded a priori assumptions prior to each element of the study then checks post element of the study. This helped to ensure the findings and analysis was not over-biased towards my personal assumptions. This addresses the issues of progressive subjectivity.

In this study, member checks were instigated to provide credibility for the data. They are highlighted as “the single most crucial technique “and involve a continuous informal or formal checking with participants and stakeholders in both the data collection and analysis to “correct errors of fact and/or interpretation” of what has been recorded, for example by checking their transcripts (Guba and Lincoln, 1989:239-240).

Lincoln and Guba (1985) suggest that checking back with participants also establishes credibility of the data. McDonnell et al., (1999) suggest that asking participants to corroborate and validate the data should alleviate this issue and increase the rigour of the research and this was the process for this study. However, with corroboration comes the risk of patients changing the data that has been provided because they have forgotten what they originally said, have changed their views or may be concerned about how their opinions or actions will viewed by their employing organisation (Easterby-Smith et al., 2002).

Sandelowski (1986) argues that member validation is flawed and as members are stakeholders with a vested interest or their own agendas to promote, therefore removing objectivity. She goes on to suggest that the memories of participants may change, both in terms of what they remember and how they remember it, which also negates the credibility and validity of member checking.

Corroboration of the data was done by providing participants of the semi-structured interviews with the opportunity to review their transcripts and make amendments or correct as they saw fit. In addition, the transcripts of each of the AR meetings were given to participants for checking. When offered the opportunity, few participants asked to see a copy of the transcripts and none made any changes. Lincoln and Guba do acknowledge, however, that the checking process can be flawed if all the participants feel they need to say they agree with the records, even if they do not. Again, this risk was reduced by providing verbatim transcripts of the meetings, which only I transcribed.

#### **4.7.2 Transferability/generalisability**

Transferability is about providing enough information in accessible language (Meyer, 2000a) to enable another to answer the question “can I transfer the results of this study to my own setting?” (Kuper et al., 2008). The characteristics of the original study (sample, settings and processes) should be sufficiently described to enable a comparative study by another researcher (Miles and Huberman, 1994). Lincoln and Guba (1985:241) claim that it is not possible to guarantee the transferability of qualitative research, however suggest that the researcher can produce enough data and depth, or “thick” description to enable another researcher to decide if the transfer can be made. That thick description should include “extensive and careful description of the time, the place, the context and the culture” (Guba and Lincoln, 1989).

It has been shown in Chapter 2 that the overarching research question of how PPI can influence planning and decision-making is one that has national pertinence for the NHS, particularly in PCTs where there is a legislative duty to carry out PPI. It can therefore be reasonably argued that the thematic concern and the site used have transferability and applicability to other healthcare settings, in particular other PCTs. Furthermore, during the reconnaissance and fact finding elements of my study I provide a comprehensive description of the context both nationally (Chapter 2) and locally (Chapters 4 and 5), the culture (Chapters 4 and 5) and an extensive account of the time, place and what was done (Chapter 3).

### **4.7.3 Dependability/reliability**

Dependability is provided by documenting the “logic of process and method decisions” to enable others to judge the extent to which the process is “established, trackable and documentable” (Guba and Lincoln, 1989:242). Reliability has been defined as “the ability to produce consistent measurements time after time” (Kumar, 2005:159). Conversely, reliability and dependability can be described as making sure research questions are clear and appropriate to the study design, ensuring transparency of the researcher’s role and the use of appropriate data collection (Miles and Huberman, 1994).

Mays and Pope (2000) state that ensuring there is rigour in a study can be done through making sure there is a transparent and robust research design and clear communication. In this study, I have reported clearly the steps I have taken, being clear about the methodology, the methods, the site and my own influence on any findings or the process as a whole.

The research was done by one researcher, me, forming my doctoral thesis, however, it has been recognised that reliability of data may be greater if more than one researcher analyses the data (Coghlan and Brannick, 2003:86-87).



The extent to which the researcher biases the findings can be recorded in a reflexivity journal (Mays and Pope, 2000). By explaining oneself as a researcher, credibility, transferability, dependability and 'confirmability' can be established (Lincoln and Guba, 1985). I maintained a reflexivity journal throughout the period of the doctoral study, recording my 'state of mind', my hopes, fears, challenges and struggles. These form part of the reflexivity section in Chapter 8. Here I clearly identify and discuss my own subjectivity towards the study, my perceptions and my values and beliefs that influenced the study.

Sandelowski (1986) disputes how finding consistencies in the stories of participants can be a method of providing validity, as the reality they talk about is only in that moment of time for that individual, and they may change their story on the next time of asking.

#### **4.7.4 Confirmability/objectivity**

Confirmability and objectivity involves checking the extent to which the data and interpretations documented can be tracked to their sources and not fabricated (Guba and Lincoln, 1989; Scott, 1990) and ensuring that there is an audit trail; enough information to follow what has happened in detail and sequentially, with the researcher making explicit their assumptions and biases (Miles and Huberman, 1994). Guba and Lincoln (1989) also propose that the researcher's own mental constructions are made clear to enable challenge and Koch and Harrington (1998:887) encourage the use of reflectivity to describe "what is going on" during the research.

Complete records were maintained of all the data that was gathered throughout the study. All documents, both those from the literature review and those in the document review, have been clearly cited and therefore open to others being

able to track and confirm the content. Personal documents and those not available publically have been stored in my own library. Digital recordings were made of all the semi-structured interviews and the AR team meetings. Full verbatim transcripts were made of these and both the recordings (stored on disc) and the transcripts are held in a locked filing cabinet. Where direct quotes have been used, the transcripts have been highlighted and then coded and therefore participants are anonymously cited in this thesis. If necessary, it would be possible to produce anonymised versions of the transcripts for inspection.

The researcher, as an insider researcher, may not always act as an external researcher might – they may have views on what needs to change, for example, and it is therefore important that any thoughts and opinions that the researcher offers are open to challenge and evaluation (Coghlan and Brannick, 2003). The insider researcher role within the organisation can cause confusion of the role and how to cope with the situation, but it is suggested that if the role within the organisation is already one of a change agent, this may be reduced (Coghlan and Brannick, 2003).

To provide confirmability and transparency and to describe my own learning through the action research (Lincoln and Guba, 1985; McNiff and Whitehead, 2006), I maintained a reflexive journal throughout the period of the study, recording my ‘state of mind’, both in words and diagrammatically using a ‘smiley’ version of me. I note any possible influences I may have on the data. Excerpts from the journal are used to form the reflexivity section in Chapter 8, providing insights into my personal preconceptions, dilemmas and struggles through the doctoral study journey.

## 4.8 Ethics

It is vital to consider the ethical aspects of what is being proposed for any study (Richards and Schwartz, 2002) and I therefore took several steps to ensure I had acted ethically throughout this study. First, written permission to carry out the proposed research was sought and received from the Deputy Chief Executive and the Chief Executive of WNPCT. No negotiation was needed, as both willingly agreed their support of my doctoral study and in terms of improving local practice and a further opportunity for the PCT to be viewed as leading in the understanding of PPI.

Consent was obtained at each step of this project, both organisational in terms of the study itself, and from participants of the interviews and the AR meetings. Staff members were given time to think about their participation before consenting, as no pressure was put on anyone to agree immediately and I was not present when they completed their forms. Emphasis was placed on the personal study of the researcher, rather than a job requirement of the organisation for staff to participate, thereby reducing any suggestion of coercion.

Kavle (1996) discusses the ethical issues of each of the research stages including obtaining participant consent, confidentiality, how the interviewees can have a say in the interpretation of what they said and the validity. It has been questioned whether informed consent can be given for something like AR, where participants do not know where the direction of travel will lead (Williamson and Prosser, 2002) . Staff might face punishment in refusing to participate in a study that has the backing of the organisation and this, too, affects the concept of informed consent (Lofman et al., 2004).

At the time of the field work I held a senior management role within WNPCT, as previously described and participants may have felt concerned about providing the 'correct' answers (Kvale, 1996:5), an issue that I addressed during the briefing when assuring the interview participant there is no 'right' or 'wrong' answer. The 'Hawthorne Effect' mentioned earlier, may mean that participants feel they have to be on their "best behaviour" whilst being audio-taped (Easterby-Smith et al., 2002:45) and although this was discussed in health terms of GP research on patients, my seniority in the PCT may have the same effect on staff members. Conversely, the interviews with the Heads and Directors of Service, Chief Executive and Board members meant I was not in a position of seniority. Plus, the emphasis was put on my role as a PhD student rather than employee.

Limitations of the interviews are not only that they were time consuming for both the researcher and the interviewee, but also the interviewee may have been unwilling or felt uncomfortable in sharing information or feelings about what was being explored. Senior managers are very aware of the "significance of information and the importance of determining what use it might be put to, and to whom" (McDonnell et al., 1999; Meyer, 2000b; Stevenson et al., 2000; Richards and Schwartz, 2002; Williamson and Prosser, 2002).

The potential to identify participants is an ethical consideration that has been widely considered (Richards and Schwartz, 2002:138). It is argued that the very nature of qualitative research means that there will be pointers as to the identify of participants (McDonnell et al., 1999) from the services they are responsible for to the way in which the participant expresses themselves. No participant was named in this study and identifying details have been altered or removed where possible. There is anonymity of the transcripts, i.e., data has coded identification exclusively known to me and stored separately in a locked cabinet in my home for the period of the doctorate. However, if there had been only one Head of Service or Director who wished to be interviewed, this may

have meant participants could be identified from the anonymous data they provided.

Easterby-Smith et al., (2002) discuss the ethical issues of the researcher taking responsibility for confidentiality and anonymity of data suggesting that the researcher has power over this. They go on to consider the ethical dilemmas of the researcher being an employee of the organisation, that participants may see observation being carried out in a covert way, where colleagues believe the researcher to be participating rather than collecting data, also the issue of knowing people quite well then 'reporting' on them. Any perceived risk that participating may affect their career was countered by the argument that this research would not have any influence on job prospects and there would be no feedback to line managers or the human resources department. This was made clear in the protocol (Turner, 2004c) and participant information sheets (see Appendix 3 and 6).

Confidentially and anonymity in the group work of action research is hard to achieve (Williamson and Prosser, 2002), but this has been addressed in my study by not identifying the group of healthcare staff nor the subject matter of the project.

This research is a formal process which has some significant time involvement for staff participating. This was, however, weighted against the anticipated benefits not only for participants and the PCT, but also the local health community (Easterby-Smith et al., 2002:50). The time constraints also affected the chosen path for deciding upon participants for the action research team, as described earlier.

Finally, there is a suggestion that the management of an organisation may be more powerful and try to exert this power to get the researcher to relinquish material that the organisation would not want to see published. The management may have a fair idea of what the research will find and the

researcher needs to be aware of the implications and repercussions if the research finds something different (Easterby-Smith et al., 2002). In this instance, the organisation was abolished before any findings were made public to the management.

Ethics approval was sought from the NHS Central Office for Research Ethics Committee (COREC) in June 2004. As part of this process, the research also had to be submitted to the Local Research Ethics Committee (LREC) and an application form was completed entitled '*Enabling PPI in the NHS*', together with the research proposal. I attended an LREC meeting to present the submission and proposal and this was approved the following month.

West Norfolk PCT was a member of East Norfolk & Waveney Research Consortium and, as such, it was necessary to submit the study proposal to the Consortium as part of their research and development policy, where it was granted full approval (see Appendix 8).

## **4.9 Chapter summary**

This chapter identified the planned implementation of the research method and the described the process that was actually implemented. It was concluded that, due to the nature of the inquiry and me as an insider researcher, action research was the most appropriate methodology, with an initial intention to follow Kemmis and McTaggart (1997) action research method, but, due to reconfiguration of PCTs, a more meandering version of Lewin's cycle was implemented. I described the rigour with which this study was implemented and detailed the ethical considerations. This next chapter provides the findings and analysis from the first part of the reconnaissance step of the action research cycle; the document review.

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## CHAPTER 5: FINDINGS AND ANALYSIS

### DOCUMENT REVIEW

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### 5.1 Introduction

The previous chapter provided an outline of the intended method for the critical document review, an important fact-finding and reconnaissance pre-step in the action research cycle (Lewin, 1946; Kemmis and McTaggart, 1997; Coghlan and Brannick, 2003). This is shown in table 5.1.

<b>Cycle</b>	<b>Action research stage</b>
<b>Pre-step</b>	Identify a general idea/thematic concern <b>Fact-finding (reconnaissance):</b> <b>Document review</b>

**Table 5.1: Stage of action research**

Beginning with an introduction to the action research site, WNPCT, this critical review will move on to consider the extent to which patient and public involvement policy was been put into practice.

I had access to my own extensive library of WNPCG/T documents, as explained in chapter 4, providing breadth and depth to the review. Most of the documents published by WNPCT where mention is made of patient and public involvement were written either by me in my role as Public Involvement Manager, by the person who was initially my line manager, a head or director of services writing a paper to the Board regarding a piece of PPI in which I participated, or a member of staff within a team that was carrying out or had completed a PPI activity or event.

A task of organising the data according to anticipated themes, as discussed in the method chapter, took place, creating initial themes according to developments in PPI in WNPCT between 1998 and 2005, which occurred in four key areas:

1. **Role development** – the creation and expansion of the role of Public Involvement Manager;
2. **Training** - the initiation and growth of training, both of staff and the public within the Trust;
3. **PPI activity and resulting change** - the increasing public involvement activity locally and the impact on planning and decision-making as a result, and;
4. **Influencing national policy and practice** - the role the PCT played in developing national policy and legislation and sharing good practice across the country.

Using thematic analysis, as described in chapter 4, a further sifting and sorting of the data took place and new themes and alternative explanations were found. It was necessary to provide a critical analysis, rather than an acceptance of the rhetoric, much of which I originally wrote in my role as Public Involvement Manager and I discuss further in my reflexivity section in chapter 8. The following two new themes were identified and each of these is taken in turn in this chapter:

1. **Prolific PPI activity, but little evidence of change** – providing analysis and discussion.
2. **Measures of success** – how activity was used as the criteria, both locally and nationally and describing two exceptions to the rule.



## **5.2 The site of the study**

To begin with an introduction to the site of the study, West Norfolk Primary Care Group (PCG) was established in shadow form during 1998 following a public consultation process undertaken during that year, with the aim of agreeing the natural communities that would form the basis for the Primary Care Groups themselves (West Norfolk Primary Care Group, 1999c). The PCG became live from 1<sup>st</sup> April 1999 as a level 2 PCG, in other words, a sub-committee of the Health Authority (West Norfolk Primary Care Group, 1999c). The Board gave its formal support to the application for Primary Care Trust status in November 1999 and the Secretary of State announced his approval in October 2000.

WNPCT, first a ‘two star’ Trust (Commission for Health Improvement, 2003) then reduced to a ‘one star’ (Healthcare Commission, 2005b), covered about 750 square miles and was home to more than 140,000 people with a budget of over £115 million (West Norfolk Primary Care Trust, 2004e). 777 members of staff were employed and over 67% of those provide services directly to the public. The PCT covered 23 local GP practices as well as providing direct services including: health visiting, district nursing, occupational therapy, palliative care, children’s services, mental health services, community hospital, community alcohol and drugs services, podiatry and speech and language therapy, intermediate care, dental services and dental access services (West Norfolk Primary Care Trust, 2004f). The PCT also commissioned services from the one local acute trust, the King’s Lynn and Wisbech Hospitals NHS Trust (Queen Elizabeth Hospital) and with other local district hospitals and specialist providers when appropriate, for example, Norfolk and Norwich University NHS Hospital Trust, Cambridge University Hospital NHS Foundation Trust (Addenbrookes) and Papworth Hospital NHS Foundation Trust (West Norfolk Primary Care Trust, 2004b).

The PCT had a large elderly population in a predominantly rural and coastal area with a rich history and heritage and a few large market towns, namely Swaffham, Hunstanton, Downham Market and King's Lynn. The PCT headquarters was based in the largest of the towns; King's Lynn. There were areas of relative deprivation and a significant number of carers and people living with one or more long-term condition such as diabetes, arthritis and osteoporosis (Rees, 2003).

Nine Directors and Heads of Service led the separate directorates; primary care, clinical governance and quality, nursing, service provision, commissioning, public health, modernisation, mental health, and finance (West Norfolk Primary Care Trust, 2004c). At the time of the study, Patient and Public Involvement sat within modernisation and the responsible officer reported directly to the Head of Department, who was also the Deputy Chief Executive (West Norfolk Primary Care Trust, 2005a).

### **5.3 Prolific PPI activity, but little evidence of influencing planning and decision-making**

Alongside the PPI health fora that consider the wider view of health services in general, the PCT carried out 46 individual PPI projects in specific services areas, from 2000 to 2006, which does not include schemes to increase the number of patient groups, for example, but specific PPI activity around a project. In 2001 alone, West Norfolk PCT reportedly organised seven public conferences, 13 focus groups, nine patient/user group meetings and two questionnaires (West Norfolk Primary Care Trust, 2002a). The consultations covered a range of topics including palliative care and HIV prevention. In 2004, WNPCT declared that they had carried out more PPI than ever before (West Norfolk Primary Care Trust, 2004a). PPI work carried out by WNPCT was posted onto a searchable public consultation database entitled 'Norfolk Consultation Finder', which was accessed via a link from the PCT's website (West Norfolk Primary Care Trust, 2006) and directly from the Your Norfolk

Your Say database (Norfolk County Council, Undated). With the abolition of WNPCT, those records have now been removed from the site.

46 PPI projects were recorded on the public database (see Appendix 3).

Examples of the range of activities are:

- PPI in enhancing endoscopy diagnostic services using questionnaires, with no change reported (Turner, 2001d),
- Public conferences with facilitated workshops on adult mental health, producing a new model of mental health services in West Norfolk (Turner, 2000a)
- Garnering young people's views on obtaining emergency contraception through the use of drama and focus groups, with the output of a recommendation for the training of receptionists (Turner, 1999)
- PPI in diabetes care via focus groups, with a report that the outputs would influence questions asked of general practices in an audit (Turner, 2000b),
- An acute services review using a series of conferences, workshops and focus groups to determine how patient services could be improved (Turner, 2001c), with no reported outcome as a result; and
- Increasing the number of Patient Participation Groups in primary care, which provide two-way communication between patients and the practice (Turner, 2001c). An evaluation into the value of PPGS and the difference they made was carried out, but no report of the analysis or outcomes was reported.

From those 46 projects, 20 did not report a change as a result, although there are a range of possibilities for why this is the case. It is possible that there was change or that the activity influence planning decision-making, but no report was published detailing the outcomes of the activity. Alternatively, the work may have been delayed, or not enough people participated to see the project through. An alternative explanation, and one that reflects the national picture, was the work simply stalled once the PPI activity had taken place. In addition,

of the 26 projects remaining, a further eight had reported a passive action as a result, usually stating that a PCT group would look at the findings or had made a commitment to do so, which provides little evidence of the influence of the PPI activity. Of the 18 remaining projects, 15 had specific actions that appeared to be taken as a direct result of the feedback from the patients and the public. However, all but one, discussed in-depth later, were minor changes, such as amending a leaflet, or changes that are hard to quantify, such as views being incorporated into a wider strategy.

The strategy claimed to ensure that participants were told what has been done, or not, as a result of PPI activity, however there are few examples of this being done. In addition, there is little evidence of the PPI activity influencing planning and decision-making in terms of direct impact on healthcare services. Instead, there are either no reported outcomes or the changes are peripheral, for example, comments feed into further work to be done at a later date or a new leaflet was designed.

An exception to this were the significant changes made following annual conferences around one specific service area, where the ‘wish lists’ of service users shifted to ‘expectations’ and finally to fruition over two to three years. It may be that because this project was managed throughout the years, with regular annual conferences, progress can be tracked, whereas other projects appear to stall once the first activity was completed. The initial service user ‘wish list’ described in the PPI in the specific healthcare service documentation received agreement as the criteria by which success would be measured from the outset. These criteria were revisited at each annual event and, by the end of the programme of activity, the by then ‘expectations; could be ‘ticked off’ as a list of completed action – a success. With the analysis from the semi-structured interviews and the action research team meetings, this example is discussed in-depth in Chapter 9.

Another exception was the work with the local black, minority and ethnic (BME) communities, where, again, a list of requirements was discussed and agreed, such as providing a quiet room for prayer or meditation and a wet room for preparation for prayer in every WNPCT venue. Their requirements were then identified as completed at the end of the project.

These are, as described, exceptions to the rule, and the document review illustrates that WNPCT was prolific with PPI activity and efficient at promoting both the need to carry out PPI activity and the importance to the organisation of doing so. Although receiving plaudits for its innovation and activity, WNPCT appears to have experienced the same 'brick wall' of the outputs of PPI activity not leading to the outcome of change to health services as a result.

## **5.4 Measures of success**

Lewin (1946:35) suggests that without a yardstick against which to measure successful engagement “there is nothing to prevent us from making the wrong conclusions and to encourage the wrong work habits.” He describes how the leader of an engagement activity can believe the plaudits of colleagues and participants for an exciting, well-staged event and use this acknowledgement as the measure of success. There is evidence of this being the case with WNPCT, where it was recognised as being ahead of other organisations nationally in terms of its public involvement and was invited to influence the national guidance at the time regarding both the principles of PPI and the activity. The work within WNPCT was considered innovative and was frequently singled out for its examples of good practice in PPI. One such was a case study via a representative sample of the local population, providing an example of public involvement in the NHS commissioning process (Allen, 2001; Child, 2001; White, 2002; Wilkinson, 2002; Gibbs, 2003; Clifton, 2004) and as a way of meeting the strategic objective of “involvement processes for service change” in the Commissioning Planning Framework (Perry, 2001).

Once again, however, there is no evidence of the PPI activity influencing planning and decision-making resulting in change to healthcare services.

WNPCT received national awards for its PPI work. First amongst these was for their work around involving young people in the decision-making process around child and adolescent mental health services. WNPCT was the runner up chosen from 40 Trust for The Guardian and Institute of Public Policy Research in Health award in Public Involvement (West Norfolk Primary Care Trust, 2001c:7). IPPR note that although there are increasing opportunities for the public to 'have a say', it "still feels like a temporary rather than permanent shift" in the way of working (2001). WNPCT's work was praised by the judges for demonstrating a commitment from the organisation to act upon the findings, however there was no evidence in the document review of the actions ever being taken.

The PCT was cited in national publications where viewpoints from experienced practitioners were sought (Turner, 2001b). Over 40 PCTs and NHS Trusts across the country and abroad approached WNPCT over the years for guidance, information and support in completing their own strategies, planning and implementing PPI, as described earlier (House of Commons Health Committee, 2007a).

Nationally, WNPCT was invited to join the Department of Health Reference Group to represent PCTs across the country, working on the toolkit and guidance for the NHS around PPI following the passing of the *Health and Social Care Act* (Skidmore et al., 2006). The Reference Group looked at establishing performance standards, providing case study examples of good practice, and offering strategies to NHS Trusts on how to carry out PPI within their organisations (Learmonth, 2009; Martin, 2009). Although the invitation demonstrates that WNPCT was on the national radar for PPI work, the reference group were invited to shape the measures of success around PPI

activity, not how NHS organisations would be held to account on how the activity influenced planning and decision-making.

WNPCT was asked to contribute further to national policy by providing the Department of Health Public Involvement Team with examples of good practice on how PPI could be developed with an aim of demonstrating how the planned 'Voices' could work alongside existing PPI (Department of Health, 2003e). The PCT provided examples of training of the public in how to help them 'have a say' in local planning and decision-making, a public conference with facilitated workshops around mental health, the forming of a young person's website to eventually allow young people to participate 'virtually' and working with the Local Strategic Partnership via the West Norfolk Public Involvement Team (NHS Alliance, 2005; House of Commons Health Committee, 2006). The Board considered the best practice project an accolade for the PCT (Picker Institute Europe, 2009). This further illustrated that the national measures of success were focussed on the process of PPI, potentially reinforcing understanding that PPI activity was the measure by which PCTs would be judged.

The NHS Executive hosted national 'Listening Events' to consider with the public, patient and voluntary groups and NHS organisations the future for PPI in the NHS (Healthcare Commission). In my role as the WNPCT Public Involvement Manager, I was chosen to facilitate and report back the discussion around the Government's plans for 'Local Voices'.

The PCT participated in several PPI pilots and pathfinders, such as the Expert Patient Programme (EPP) (Association of Healthcare Communicators, 2001; Norfolk County Council Social Services and Authority, 2001; Institute of Public Policy Research (IPPR), 2002:33), Patient Advice and Liaison Service (Turner, 2001b), NHS Direct Patient Information Points (Shannon, 2004:12) and the UK pilot of 'Consultation Finder', as discussed earlier, making them amongst the first to implement new ways of working in the NHS.

In the evaluation of the EPP pilot the PCT was highlighted (albeit anonymously) as being an example of a Trust that had invested time and effort in making EPP a success, involving the voluntary sector to help steer the Programme, using participants to inform GPs and working in partnership with other agencies and carers (NHS Alliance, 2004a).

WNPCT was mentioned as an example of good practice for working with black, minority and ethnic (BME) communities, for its guides on how to involve people the NHS traditionally find 'hard to reach', the PCT's PPI training, induction of new staff in the ethos of PPI and the systems the PCT uses to improve communication in PPI activities (Department of Health, 2003d, 2003e).

The National Association for Patient Participation (NAPP) also highlighted the work with BME groups by the PCT as an example in their PPI Best Practice project (McDevitt, 2001) and the Equal Opportunities Commission has asked the PCT to pilot some best practice work around gender issues (Turner, 2001e). Once again, this is an example of the measure of success being the activity of PPI, rather than the outcomes of changes to healthcare as a result.

Other awards includes two national awards for its publication '*Well Being*', which was initially a vehicle for enabling local people to find out about ways of getting involved (West Norfolk Primary Care Trust, 2001b). WNPCT was the runner-up in the NHS Alliance Acorn Awards 2004 for its 'whole systems' approach to PPI within the PCT (Court, 2001).

Measuring patient experience was seen by interviewees as 'audit' not PPI. This was shown in the new Norfolk Primary Care Trust staff structure where 'measuring the patient experience' was a role within the audit and governance



department, not the Communications and PPI Department (Norfolk Primary Care Trust, 2007).

## **5.5 Chapter summary**

In this chapter it has been demonstrated that WNPCT was prolific in its PPI activity. This activity was often high-profile, receiving extensive publicity and winning awards and accolades from the Department of Health and other national bodies. It was clear that the yardstick of success by which WNPCT and my own practice was measured, was the extent, breadth and innovation of the *activity*, with little mention of the requirement for a demonstration or evidence of change to patient healthcare services as a result.

It was also shown that little evidence of change to healthcare as a result of PPI activity was reported. There were few examples of significant influence and rather than an 'atypical' PCT, WNPCT experience the same brick wall between PPI outputs and outcomes to healthcare as other PCTs across the country.

This next chapter investigated these issues further, via the analysis of the semi-structured interviews, to explore the values and beliefs of staff regarding PPI that influences planning and decision making and leads to change.

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# CHAPTER 6: FINDINGS AND ANALYSIS

## SEMI-STRUCTURED INTERVIEWS

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### 6.1 Introduction

For the purposes of this study, and to minimise the risk of methodological bias and provide triangulation, I used three different data collection tools in the pre-step and first cycle of the action research. Firstly, a document review; secondly, semi-structured interviews and; thirdly, the formation and work of the Action Research team, which included reflective diaries. With chapters 3 and 4 setting out the background and methodology used in the research and chapter 5 providing a critical document review, this chapter provides the findings and analysis of the semi-structured interviews. This stage of the action research process is illustrated in the table below:

Cycle	Action research stage
Pre-step	Identify a general idea/thematic concern <b>Fact-finding (reconnaissance):</b> Document review <b>Semi-structured interviews</b>

**Table 6.1: Stage of action research**

The aim of this part of the study was not just to understand what respondents thought, but also *why* they thought it. Throughout this report the perceptions are recorded, not facts – participants may hold views that are based on incorrect information. Throughout the report, use is made of verbatim comments. While these have been selected to exemplify a particular view, it is important to remember that the views expressed do not always represent the views of all participants.

Easterby-Smith et al., (2002) suggest that senior managers are often proficient and experienced at being interviewed, which may explain why, despite a conscious effort being made to interview employees in an environment where they would not feel inhibited to speak, all the Heads and Directors of Service were interviewed in their own offices, or mine, at their instigation. Reasons they cited included the lack of availability of meeting rooms, lack of time to travel to another venue and pressure of work commitments.

In analysing findings, I conducted a process of thematic analysis, in which data from the interviews was examined closely for key patterns and themes, as described in chapter 4.

## **6.2 Thematic analysis**

Prior to the semi-structured interviews the questions were pre-themed into six categories for ease of analysis (see Appendix 4), a form of “anticipatory data reduction” (Miles and Huberman, 1994:10):

1. **Background information:** these questions were primarily asked as an ice-breaker but also gave an opportunity to determine if the different backgrounds of participants (e.g. clinical or managerial) influenced their responses, if their length of time employed in the NHS made a difference to their answers, and by asking the number of staff for which they were responsible explore if their attitudes cascade down or up and vice versa.
2. **Understanding:** these questions explored the knowledge and understanding of participants in terms of definitions of PPI, the legislation or the PCTs vision and PPI training.

3. **Experience:** participants were asked for any experience of PPI within the PCT, then within their own department. Furthermore, they were asked if they believed there had been changes in services as a result, or that had impacted on their own work.
4. **Values and beliefs:** these questions examined how important participants believed PPI to be, how achievable it was and the barriers and solutions around PPI. The questions then probed into the priority and importance of PPI within their own working day. Finally, having established the above, participants were asked if they felt the PCT was committed to PPI and why.
5. **Changes:** these questions asked participants if they felt PPI was working in the local NHS and for their ideas for developing PPI.
6. **Portability:** in the midst of designing the interview questions, the PCT was notified it was about to embark on a period of reconfiguration (see Chapter 5) and so this question was asked in order to explore whether, in the opinion of participants, PPI would be something that had value for them or the new organisation, once the ‘dust had settled’ and the PCTs merged into one.

Together, the questions had five key aims, as described in 1.2.

Examples of field research about attitudes and use of cocaine leaves in Peru demonstrated how asking one question elicited the same answers from the sample, suggesting reliability of the data (Kirk and Miller, 1986). However, when they tried another, less obvious question, the answers on the same subject were very different, questioning the validity of the original data – an error of theoretical validity, where participants had followed the ‘party line’ providing answers they believed they were expected to give. I considered whether my own questions during the semi-structured interviews were equally flawed.

Participants all agreed that PPI was important and supported, until I probed further by asking where PPI fitted into their day jobs, or where I asked them to provide me with an example. Potentially, I had asked the ‘wrong’ questions and they had provided the perceived approved response, but with further probing, different answers emerged.

Once the transcripts from the interviews were typed up, I read and re-read them a number of times until I was very familiar with each participant’s responses. Each question was then inserted as a header by category into a spreadsheet and key points and quotes pulled out for each of the 25 interviewees under each of the question headers. The answers did not always fit neatly into the question asked, so thorough reading of the transcripts was required and points and answers pulled out and entered as appropriate. The background sections of the interviews were largely unused as participants gave their full ‘career history’ and concentrated on this area of the interview, which resulted in a great deal of superfluous data and wasted time in terms of interviewing and transcribing for the purposes of this study. On reflection, I would do this differently next time, asking specific questions relating to the research question or demographic data I required.

Once key points from the answers to questions were identified, they were themed according to the findings, rather than the original interview questions. I had some internal debate about the theming (see reflexivity Chapter 8). In developing the interview questions, I had already themed them according to anticipated or potential responses. Did I ignore these and start again, even though I had sub-themes in each category? If I started again, what themes would I find? Should I do both?

In addition, I had originally considered the findings to be very positive in terms of PPI being successful within WNPCT and all staff being ‘signed up’ to this way of working: something I found personally gratifying and something of which I could be proud. However, several more months passed before I was

able to look at the transcripts again and I found myself interpreting the findings in a very different light.

This re-theming was done by taking all of the individual responses I had already identified for my initial theming according to the interview questions out of sequence to enable a different perspective. This fits with the intention to test the emergent hypothesis against the data and search for alternative explanations, as described in 4.6. I then looked at each quote in turn to see whether there were any similarities in responses and began to sort through as patterns emerged. There was similarity in terms, for example 'lay representatives' and in references to the Public Involvement Manager's job. I carried on doing this until I had scrutinised all of the quotes several times, placing them in piles, then checking and re-checking to see if new patterns emerged from this lateral thinking. Sometimes, a quote fitted a new theme, but by way of disagreeing with the other respondents.

As I read further, the 'changes' appeared to all be peripheral. I did not see any evidence of people believing that patient care had changed as a result or that improvements had been made. Commitment to PPI appeared to be based on assumptions and was not a priority in their own roles. The new themes I constructed reflected this new, more negative – or perhaps less subjective - view. This is explored further in Chapter 8.

Finally, the following themes and sub-themes were identified, based on my analysis of the findings:

**1. PPI is important for the organisation but not the individual member of staff**

- a. Organisation values PPI
- b. Assumptions
- c. "We don't deal with the public"
- d. "The 'Public Involvement Manager' does it"

## **2. PPI is appropriate for some decisions and not others**

- a. Issues around confidentiality
- b. Negative experience of 'lay reps'
- c. Patients are not 'able'
- d. Raises expectations
- e. Slows the process

## **3. Change resulting from PPI was peripheral**

- a. Peripheral
- b. Staff are patients and patients are people

## **4. Fear of the future**

- a. Locality working lost
- b. Organisational change will take priority

## **5. Enabling factors**

It is perhaps important to note here that these themes were not taken back to the participants of the semi-structured interview participants for validation or accuracy. By the time this theming took place, the original organisation for the study no longer existed and staff had moved into new organisations or had left the NHS. This is a potential limitation discussed later in Chapter 9.

## **6.3 Background Information**

Background information is given regarding the knowledge and understanding of PPI by participants, which gives context to their answers. Each of the themes and sub themes above are then taken in turn, exploring the findings, giving examples to illustrate a particular view.

### **6.3.1 Years in service and responsibility for other staff**

Most of the participants had in excess of 15 year's employment in the NHS, with many staff, both clinical and managerial, each accruing between 25-40 years of service.

Just over half the participants described their jobs as managerial in some way, whilst another 40% said their role was clinical or medical, including staff on pharmacy contracts. 8% were administrative.

36% of participants said they did not manage staff, but these were mainly people with a clinical or medical role who explained that they did not line manage in the traditional sense, but provided clinical supervision.

40% managed up to ten people, though were often 'grandparents' to several more. 12% said they were responsible for over 30 members of staff and into the hundreds.

### **6.3.2 Experience, knowledge and understanding of PPI**

Over half the participants said they knew nothing about any policies or legislation around PPI. Less than a quarter knew the name of the Act which enshrined PPI in law.

A third of participants, encompassing both clinicians and managers, did not know what the PCT's vision was for PPI, as explored later in this chapter. 56% said they assumed there was a vision due to the role of a Public Involvement Manager within the organisation. This, too, is explored in greater detail later in the chapter.

Of the participants who self-described themselves of being in clinical or medical roles, 60% had no experience of PPI within the PCT, whereas the



majority of those in a managerial role said they had some experience or knowledge of high profile conferences, lay representatives on committees or some other method of obtaining patient views.

When asked to give examples where participants had experience of PPI within their own department, most people cited surveys and questionnaires, presentations at Board or to patient groups, conferences and user groups. However, a wide variety of other methods were indicated, including suggestion boxes, discovery interviews, patient diaries and focus groups.

### **6.3.3 Definitions**

Heads and Directors of Services identified different ‘levels’, ‘elements’ and ‘forms’ of PPI, a distinction that was recognised some years later. Participants differentiated between PPI on a collective level looking at service changes, measuring the patient experience and patients being involved in their own care. In addition, distinctive processes were identified ranging from a ‘tick box exercise’ of telling people about decisions already made (consultation) through to finding out the views of people who had used services (genuine involvement).

One interviewee (HS6) described three “elements” for when PPI should be carried out, which were supported by other members of staff:

1. Strategically in developing services; “listening to them as we plan and develop services,” how the organisation works and can be improved and “higher level stuff”.
2. Involvement in their own healthcare.
3. Learning from the experiences of patients to make improvements in patient care: ‘micro-change’, ‘audit’.

Another head of service (HS21) identified four different ‘forms’:

1. A process of consultation when changing a service – asking: 'are you happy with that?'
2. Proactive, to make sure we got it right where there is a genuine desire to get patient and public input.
3. A “rubber stamp job” where the outcome is known but proposals might be 'tweaked around the edges'.
4. Measuring the patient experience: the “more interesting part is the 'micro' where people who've been treated give their experiences.”

Several participants described PPI as a partnership or a balance between provider/commissioner and service user. One Head of Service explained it: "I see it as a pair of scales and it's about tipping the balance so that the needs of patients and service delivery are in equilibrium." (P6)

A common theme for participants was to define PPI by what they perceived it is not. It was not 'just consultation' and not 'tokenism' or 'lip service' nor cherry-picked lay representatives on committees, but 'genuine', 'active' 'involvement'.

#### **6.4 PPI is important for the organisation, but not for individual members of staff**

Most members of staff claimed that they believed PPI was important on a number of levels: to ensure the right services, in the right place at the right time for patients, to ensure people 'have a say' or to empower people, because it was a 'must-do' and as a 'value' they felt it was crucial to the organisation. A positive experience was most often given by a head of service or director. Language used to describe PPI in the PCT included 'positive', 'successful', 'effective' and 'productive'. However, this was usually followed with a 'but...'

It became apparent that although PPI was important for the organisation, there was only some decision-making in which it was felt patients and the public

could and should be involved, that it was not a priority for them in their 'day-job' as they were responsible for direct patient care or had other more important aspects of their own work and that the Public Involvement Manager took care of PPI anyway.

Participants believed that PPI was working well within the PCT and often better than in other NHS organisations, but held this conviction from a set of assumptions, rather than first-hand experience of changes or improvement in patient care as a direct result of PPI.

Moreover, it became apparent very quickly that participants did not have the same understanding of the term 'patient and public involvement'. The post of Public Involvement Manager (PIM) was formed in 2000 and the title is significant in light of the misunderstanding of terms, as it only refers to 'public' involvement. The inclusion of the word 'patient' was introduced as an acronym in Department of Health documents in 2001 (Department of Health, 2001c), but the job title of PIM within WNPCT was not changed to reflect this. It is possible that the role of PIM was so key to the views and assumptions of staff, the 'PPI' aspect was not discerned. All these issues are described further in each of the sub-themes below.

#### **6.4.1 Organisation values PPI**

Most participants, at all staff grade levels, perceived that the organisation valued PPI and was committed to it. This belief came from management or Board papers they had read, through knowledge of high profile and contentious public meetings (for example, around the closure of a cottage hospital or the future of adult mental health services, the former of which had been covered extensively in the local media), through the leadership of the organisation (particularly the Chairman and Chief Executive) and, significantly, through the role of the Public Involvement Manager. In many cases there was a sense of pride that the PCT was better at doing PPI than other local NHS Trusts and

potentially better than others in the country. Heads and Directors of services were more specific when describing the vision and commitment of the PCT to PPI.

### **Examples of perception of the organisation valuing PPI**

*“We see it as one of our fundamental aims.... One of our core objectives... and we saw it from day one as something that was very important to us... Certainly at the Board and Exec level, very much (committed).”*  
(P4)

*“I think its commitment is very high and very clear and very transparent about (it) – the PCT sees that as something that is to be valued, basically.”* (P8)

*“The overall aspiration of the PCT is to be good on public involvement.”* (P10)

*“The Chairman doesn’t only just talk about it, but really is interested in it and really wants to know what we’ve done about it... and that’s not only the chair, there’s the other non-executive directors as well.”*  
(P25)

*“I think there’s a commitment and a dedication to ensure that it happens.”* (P7)

*“The old fashioned consultation - think about it, write it, send it out, wait for comments, ignore comments and then publish it – type role is now gone, and rightly so.”*  
(P19)

Clinicians and grades beneath director level, though not as explicit, felt that the commitment and value was more implied. They had been influenced by the media, internal publicity, via meetings and the role of the Public Involvement Manager.

## **Examples of influences on perception of PCT valuing PPI**

*“By the fact that they’ve got a public involvement manager and that it’s talked about regularly and you see it in newsletters. All what has happened with (PPI around the closure of the cottage hospital) was very much involving the public in what was actually a time when you’d probably want to hide from the public and not involve them.” (P3)*

*“It’s your role, knowing that we’ve got somebody in post that’s employed to do that. I mean, there must be legislation, I have to say – there’s got to be otherwise you wouldn’t be doing it, so somebody higher up has decided that’s what we’ll be doing.” (P2)*

*“Well, I know about some of the things that you’ve done and – like the Expert Patient role and the various things you’ve actually run, meetings that you’ve run on various topics...” (P12)*

*“We have a PPI representative (on the Board), we’re aware that the Trust was very much involved in the documentation from the Government, we know that they’re very keen to implement it... Letters, emails, it’s brought up at meetings that people attend... we get people coming to the meetings and talking to us about PPI and telling us how important it is.” (P13)*

*“I think West Norfolk PCT ... has invested a lot of money in it. From the Chief Exec, and I’d say yourself as well, putting a lot of effort into it, really.” (P15)*

When describing the PCT’s commitment to PPI, it was often as a comparison with other NHS organisations participants agreed their organisation was seen as ‘better’ at PPI.

## **Examples of perception of PPI not working in the acute hospital and being ‘better’ in the PCT**

*“Not in the (acute hospital) I don’t think at all. I think that’s very poor and the public aren’t involved enough there. I think there’s a stark contrast on the importance placed on it.” (P3)*

*“I think we can do an awful lot more and do it better, but I think we do it quite well and, if we compare the way we do it with how some others are placed to do it, we do it better than other people. I’m proud of what we’ve achieved.” (P4)*

*“I’m not sure about the hospital though... I don’t see a lot of it (PPI) elsewhere.” (P8)*

*“Again, you compare it to other places, but other places that I’ve worked, it’s not as evident and, if you compare it to neighbouring PCTs, it’s certainly not as evident. And at the (acute trust), I think – again, only from my experience and dealings with people – it’s like: ‘oh \*\*\*\*\*, we’ve got to talk to those... it would be great running this service if it wasn’t for the bloody patients’.” (P25)*

*“I think that it’s been fantastically successful and I have to say, without patronising, that of all the engagement we’ve done in the past... some of the public awareness that we’ve got here is second to none.” (P11)*

#### **6.4.2 Assumptions**

Other than by heads and directors of service, assumptions were made that the PCT (a) must have a vision, (b) have commitment to PPI, (c) would be doing PPI and, (d) that it was ‘working’ locally, based on PPI being a ‘must-do’ for the PCT and the NHS as a whole striving to be ‘patient-centred’. Heads and directors of service were more able to be specific, perhaps because they had

either been directly involved in a PPI activity as the responsible commissioning lead, or in setting and agreeing local PPI policy as a member of the Board.

### **Examples of the assumptions made by participants**

*“I think patient and public involvement must be working; otherwise (the PCT) wouldn’t be targeting its resources effectively.” (P17)*

*“There’s no evidence to say that it isn’t (working), because if it wasn’t, there again, I think that people would be grumbling a lot more and I really don’t hear of any grumbings here.” (P22)*

*“I’m assuming there would be almost a legal commitment or a... because obviously, there’s legislation out there and with most legislation there’s organisations that are tasked with making sure that that’s actually happening... so obviously, there is a commitment for the PCT to be doing public consult... public involvement, but I wouldn’t know to what extent that was, or who it was even, really, that was tasked to make sure it happens.” (P18)*

*“I wouldn’t really know other than I suppose they support public involvement, but how that happens I’m not really sure. Because it’s a patient-led service, isn’t it, really?” (P16)*

*“And I suppose, yeah, indirectly, it’s the management team and the executive that are supporting it.” (P2)*

*“It’s something we have to be seen to be doing, so the management are obviously committed to doing it because they have to be.” (P7)*

### 6.4.3 “We don’t deal with ‘the public’”

Many participants found the term ‘Patient and Public Involvement’ confusing. Participants who saw themselves as providing services to patients (doctors, nurses and midwives, pharmacists, healthcare scientists etc) thought of ‘public involvement’ as separate to involving patients: ‘patients’ are not ‘the public’. They perceived that ‘the public’ were people who had never used their service and had never been patients.

#### Examples of ‘patients’ not being ‘the public’

*“It’s that word ‘public involvement’ that I keep getting snagged on because, for us, that translates as involving people (in their own healthcare). Involving Joe Public who has never had anything to do with our service...” (P1)*

*“My role is on a one-to-one basis rather than gaining opinion from the public as a group on our role.” (P18)*

*“You could have a debate about: are patients the public and are the public patients.” (P4)*

Furthermore, clinicians and care-providers perceived ‘patient involvement’ to be the involvement of patients in their own healthcare decision-making. Participants often did not recognise the work they did as PPI, seeing it as ‘audit’ or ‘just something they do’ in terms of patients being involved in their own healthcare or feeding back directly on their experiences of care within a ward, department, or community service.

Chapter 4 outlined the training available to staff, which included ‘PPI – the basics – why you?’, discovery interviews, facilitation skills, and questionnaire training. These opportunities were advertised in all-staff emails, the PPI strategy and in the annual report. The content of the PPI ‘basics’ training



allowed participants to explore definitions of PPI and the different types of public, their attitudes, beliefs and behaviours around the importance of PPI, techniques and managing the resulting change. There was then a focus on how they would put PPI into action within their own ward, service or department.

However, the promotional literature about the training was entitled 'public involvement' training. A number of clinicians and care-providing staff saw PPI training advertised but focussed on the word 'public' and, as they dealt with 'patients' not the public, they felt the training was not relevant for them. Nine out of 25 participants had not received any training and would not want it – the majority gave their reason for this as their role not being about 'the public'.

### **Examples of PPI training not perceived as being relevant**

*"I don't deal with the public - I deal with patients and patients and their carers. They're not public... so I can't see how (PPI training) would help me." (P17)*

*"We're a profession, not managers". (P2)*

*"You should be there for the patient... too much money (is) spent f\*rt- \*rsing about." (P20)*

Those who said they had not had PPI training but would like some (six out of 25), made assumptions that it would have a clinical focus, such as using more patient-sensitive language, finding out about cultural diversity, and having clinical peer supervision.

Clinicians and those providing care to patients did not recognise 'PPI' as something they did, although during the course of interviews, it became clear that a number of initiatives were being carried out from suggestion boxes,

surveys and questionnaires to patient focus group on wards. Measuring ‘patient satisfaction’ in this way was seen as ‘audit’ not PPI, or just something they do.

### **Examples of PPI not being recognised as such**

*“It is very difficult to talk about because we do it without knowing that we’ve done it and without knowing that it is an issue or a big deal.” (P1)*

*“I certainly don’t have a bit of my working week that’s dedicated to public involvement work...It’s integral to what you do and in a way that’s why it’s difficult to talk about it.” (P7)*

Participants in a self-described ‘management’ role indicated that they supported PPI, though they do not do it themselves. It was not seen as relevant for clinicians to do as they perceived it to be a managerial role.

### **Examples of PPI being a management role**

*“It’s not something I really need to think about, cos at the end of the day, I’m one of the workers on the ground floor and I just sort of get on with what I have to do and the rest of it just goes over my head.” (P20)*

*“We’re a profession, not managers.” (P2)*

## **6.4.4 “It’s the Public Involvement Manager’s job”**

Having seen that clinicians felt PPI was not their job as they dealt with patients, and directors and managers perceive that their role is to support PPI but not to do it themselves, the role of the Public Involvement Manager was highlighted as paramount for implementing PPI.

Most participants knew about PPI because of the Public Involvement Manager (PIM) role. They had either been involved with the PIM in projects, read about PPI activity managed by the PIM through the media and internal publicity, had presentations at team and Board meetings or induction, or been offered training by the PIM.

Participants all agreed that PPI was 'important', 'fundamental', 'vital' and something the PCT had to do to ensure that the local NHS met the needs of local people. Key to staff believing that the PCT supported this vision for PPI was through the organisation having a role of a Public Involvement Manager (PIM).

Despite valuing PPI for the organisation, when asked where PPI was in terms of their own work priorities, most participants rated it either low or not something they would be doing. Both clinicians and practitioners and managers and heads of service alike, saw PPI as something that the PIM would do.

### **Examples of participants highlighting PPI to be the PIM's job**

*"I rely on the experts to tell me what my role (in PPI) should then be... We've got you." (P19).*

*"I rely on other people to have the full grasp of (PPI legislation) and to make sure that, at particular times, it's drawn to my attention." (P10)*

*"It's probably something that you took on in your role and there's two reasons for that. One is that some of us have confidence in you and say: 'that's Trish's job and she does it very well and she's a pain in the \*\*\*\* about it, but she does it well and we don't have to worry,' so we wouldn't take that much ownership of it. (Two is that) we could piggy-back onto the work that you do and take credit for it without doing much more." (P11)*

*“You have this conundrum of, if you have somebody doing public involvement, there’s always a danger: ‘that is public involvement, I’ve got that sorted because somebody’s doing it’, and it’s how you genuinely make sure that everybody, other than the public involvement people, genuinely do think of public involvement... I think it’s the questions that we have discussed before really about at what point could you actually say that this job is done, ‘I don’t need to do it any more because everyone else is now doing it’?” (P10)*

*“That’s why we have Trish!” (P21)*

*“I don’t know (how portable PPI is) because, at the end of the day Trish, you’re one person and you’ll have to find a home in one place or another.” (P21)*

Furthermore, a reduction in the role of the PIM (due to a move to project managing the reconfiguration) was perceived as an indication of lack of real commitment by the PCT when something is of a higher priority, which again highlights the importance of the PIM role as how PPI ‘gets done’.

Conversely, the exceptions that prove the rule:

*“I would be disappointed if staff felt that public involvement was your job (the PIM) and not everybody’s job.” (P4)*

*“We’ve got managers and leaders, if you like, who are challenging around the whole thing and they don’t just expect it to be done by Trish... there is a bit about ‘we need Trish to do some work on this’ or ‘we need Trish involved’, but they would expect other people to do it as part of their job as well, it’s not just that, ‘well, we’ve got a PPI manager and if it doesn’t work it’s their fault’... there’s an expectation that it’s part of what everybody does, I think.” (P25)*

## 6.5 PPI is appropriate for some decisions and not for others

Most participants felt that PPI in measuring the patient experience, such as patients giving their views on staff attitudes and behaviours, was appropriate, as was involvement in processes, such as planning a new service, determining opening hours and consulting on major changes to services. However, they were also clear that there are decisions patients should not be involved in, such as clinical decisions (the ‘what’ as opposed to the ‘how’) and things that need quick decisions (e.g. when bidding for Department of Health funding or when there are tight national targets and deadlines). In addition, PPI was not always deemed appropriate in decision-making when patients were not ‘representative’ of anyone and had their ‘own agendas’, where they might not be ‘able’ due to their health condition or because the subject being discussed was too complex or sensitive, e.g. involving strategic financial decisions or prioritising commissioning.

*“It’s easier when you are looking at a specific service and you can bring particular patients in. It’s easier when you have a practice that you can bring a patient group in that supports that practice. It’s more difficult when you are looking at the decisions of the PCT.” (P4)*

Conversely, participants believed that PPI is essential to ‘crafting’ and determining how services should be provided that people will need and use. They felt that if patients were not involved, the PCT would be in danger of providing services that people do not want or it would be in the wrong place, or would waste tax payers money.

*“It’s their community at the end of the day and if you’ve got an area that needs a bit more attention with something, if they don’t speak up and you don’t speak to them about it, then they’re not going to get that service are they? You need to find out what they need to provide the service. You could provide the service and there’s*

*nobody there that needs it, so there's no point in doing it is there?" (P20)*

### **6.5.1 Issues around confidentiality**

Participants felt that patients and the public should not be involved when information or decisions are commercially sensitive.

*"I don't think patients should be asked to make huge decisions on budgetary matters, I don't think that's proper... However, I do think that their perspective should be represented." (P6)*

*"Do I want to bring in the public and mess up the process and not get (x million pounds) and (x clinicians) because the world and his wife know about it, or do I beaver away in the background, do what common sense tells me is in the public interest?" (P5)*

*"At the end of the day, if people's jobs are on the line because we've got to restore financial balance, then it would be silly of me to say 'well, the patient and public thing is the most important, because in that context, finance is.'" (P21)*

In addition, patients should not be involved in staff confidentiality issues, e.g. clinical incidents. One member of staff explained that they had a lay representative on a clinical group that examined clinical incidents, where patient care had not 'gone well'. They described their discomfort that this made their team look unprofessional and not acting as a cohesive unit and that much was left unsaid due to a fear of breach of patient confidentiality. They pointed out that even the lay rep looked uncomfortable, questioning their own presence at the meeting.

## 6.5.2 Negative experience of ‘lay reps’

As described in Chapter 4, the PCT encouraged lay representatives - members of the public who had experienced a particular service or who had a specific interest - to join committees and decision-making groups. This included a member of the Community Health Council, then superseded by a member of the Patient and Public Involvement Forum, on the Board of the PCT.

Many participants had experienced ‘lay representatives on committees’ but reported that this was often a negative experience, with lay reps not considered to be representative, useful or valuable. Others said they felt that the lay rep almost became ‘part of the PCT’ and a member of staff, albeit it unpaid, rather than a patient, and therefore they did not find that helpful or relevant. Participants reported that lay reps with whom they had worked were not ‘a typical patient.’ It is recognised that lay reps are often people who sit on many committees, who then dominate public involvement activities – the ‘usual suspects’ and can alienate others getting involved and the organisation looking to seek genuine public involvement. Others have highlighted the dichotomy of needing ‘ordinary’ people to represent the public and have knowledge of the views of the public, but that ordinary people would struggle to have the scientific/managerial knowledge necessary to do the job effectively. Conversely, lay reps were considered by participants to be ex-patients with their own personal agenda and unwillingness to take part in the wider discussions.

There was confusion about the role of the ‘lay representative.’ They questioned whether the patient was representative of other patients or a patient group, or if their role is to be present as an individual to give a patient perspective. This lack of representation from a lay rep is acknowledged in the practice guidance around the 2001 legislation and in not a new one (McIver, 1999). Staff felt that it was unclear when they should be involved (in all committees, for all

discussions or just some?) and the process for involving lay reps had not been set out.

To illustrate the negative view of lay reps, when participants were asked for their definition of PPI, many used the example of patient reps to describe what it was not. For example, it was:

*“Not getting the 'right' patient on the group, where the system is "worked", either by the staff putting someone on who'll give the 'right' answer or the patients who want to lobby.” (P5)*

*“Not just a 'lay rep'.” (P8)*

#### **Examples of participants negative perceptions of lay reps:**

*“Sometimes we struggle to know what's going on, let alone a member of the public and actually then having to explain to them what's going on... sometimes you just wonder if it's useful.” (P19)*

*“I have come across instance in the past where the system will be worked. I've heard (X Trust) talking about getting the 'right' patient on the group when they wanted a particular outcome for service development.” (P5)*

*“You sometimes get particular patients who have an axe to grind and who are really a single item issue... because he'd has a bad experience and he was going to tell everybody, every time.” (P4)*

*“I don't think the motivation to get involved in the first place is a problem. It's when they can't leave that baggage behind... it's unresolved baggage. I think we're all too polite and probably politically scared... for a senior manager to turn around to a patient rep and say 'I'm sorry, but your contribution to the meetings has*



*been entirely disruptive’... you’d get your knuckles rapped.” (P4)*

*“Individuals with a 'bee in their bonnet...obscuring what's the real genuine issue.” (P21)*

### **6.5.3 Patients not ‘able’**

In common with the findings of other research into the barriers preventing effective PPI as highlighted in Chapter 2, many participants questioned if patients are able to be involved in planning and decision-making (Rutter et al., 2004).

Reasons given for this was due to the ill health or complex physical or mental disability of the patients, their age (for example young children), that they would not be able to ‘grasp’ the complicated NHS issues and their lack of objectivity.

*“However I put this it’s going to sound arrogant... some of the issues are complex and very subtle and I don’t know how we could engender a real understanding of these issues in the people we would need to involve such that they could contribute. So I know that sounds really not okay – not politically correct – but within our services, that’s the reality... They’ve all got a very strong emotional investment in the outcomes of these decisions.” (P21)*

*“I think there are some patients, at some particular times and stages of their illness where it’s not appropriate to be asking them for their opinions of their treatment.” (P7)*

*“Either they’ve had a good experience or they’ve had a bad experience... they can’t objectively assess what has happened to them because they were ill at the time and*

*they tend to view their experience depending on the outcome.” (P17)*

*“I guess it depends on the issues... if the public is engaged in service redesign, that’s absolutely the right way to do things, I don’t argue with it. When they’re engaged in... a classic example - we’ll say the commissioning process - I’m less sure about to what extent the public can be engaged in some of those processes, because I have real fears about lobby group pressure. If you look at the Oregon experiments, where they’ve had service prioritisations, the needs of vulnerable groups get put to the bottom of the list: if you’ve got cystic fibrosis you won’t get treatment because not many people know many people with cystic fibrosis... So I’m very wary of processes that might engage the public in deciding prioritising the needs of a community groups because you either get very small lobby groups or lobby groups who don’t have the bigger picture.” (P21)*

*“A classic example of how public involvement doesn’t work where you’ve actually got irrational individuals, you know, where they’ve got a view, but they’re barking mad, basically. They can shout and rave, but actually they’re just obscuring what’s the real genuine issue. Some of the people sat looking embarrassed, you know: ‘can you listen to us, not the ranting?’ It was just someone who’d got a bee in their bonnet. There were people from the same organisation that did have genuine issues who wanted to speak through and it was better to placate him but listen to people who had the genuine issues. I mean, not everybody in the public are going to talk some common sense. At the end of the day, some people are a lot better informed than others and, yes, everyone’s got a right to be heard but not everybody’s got a right for their view to be the right view.” (P21)*

*“I don’t think patients should be asked to make huge decisions on budgetary matters - I don’t think it’s proper. However, I do think their perspective should be represented.” (P6)*

## 6.5.4 Raising expectations

Many participants felt that involving the public in some decisions would have the affect of raising expectations that could then not be met. Again, this reflects the findings of other research on the barriers for effective PPI, highlighted in Chapter 2.

*“For patients it might be very emotive - it’s about their own personal journey and their own personal experience and they will always bring that and, at the end of the day, that’s partly what we want so they can have a lot to say about that and that’s very important - to me personally - more important than the other stuff. But professionals will be looking at it perhaps from a realistic view as to what they can do with the resources that they’ve got and with their own baggage and their own defences, because they feel they represent a certain area and it’s particularly difficult if patients are criticising that - patients or their representatives. And so when you’re facilitating it’s not just about what people say, it’s about what they don’t say and managing that.” (P3)*

*“You always want the ideal and the ideal is very difficult to deliver. If you ask them what they want and you can’t give them what they want, then what do you do with that information, really? Because you thought you could provide a service, nobody wants it - they want something else – you can’t provide something else. You’ve asked them something, so raised their expectations, because you’ve asked them initially, and then you can’t do anything... but you need to ask them in the first place to establish what services you need and where to take things!” (P18)*

*“Why ask people what they want when you know there’s not a hope in hell of being able to deliver it?” (P1)*

Conversely, it was acknowledged that the public might have the ability to appreciate the competing pressures and demands on the finite resources of the NHS, providing time was taken to explain.

*"If you say you're going to do things, if you can't do it, say why you can't, then even if you've got someone with a really strong opinion they will understand restrictions."*  
(P25)

### **6.5.5 Slows the process**

A theme emerged of PPI slowing down decision-making and/or the change process, therefore PPI either (a) needs to start much earlier when the project or idea is in the 'twinkle of the eye' stages or (b) be implemented much faster. This made staff reticent to involve them, as the NHS decision-making process meant progressing work already took long enough. Other members of staff made the point that there were occasions when pieces of work had to be progressed swiftly, so these were times when the decisions had to be made on the knowledge and experience of the person making the decision with no PPI.

Conversely it was recognised that not involving the public initially could lead to delays later:

*"If I have to propose a plan that's going to have an impact on front-line services, then the public would be involved - because if I don't, I might be delayed anyway and I might not achieve my ends."* (P21)

## **6.6 Change resulting from PPI was peripheral**

### **6.6.1 Measures of success**

No key performance indicators were yet in place to measure outcomes of PPI and participants felt that it was not clear how PPI could be assessed or evaluated to see if it was 'working', what would be deemed a successes and what the measurement of success would be. They questioned if improved

understanding of the pressures the NHS faces, such as being limited by finite resources or having to meet a Government target, was a ‘good’ or ‘successful’ outcome. Moreover, they queried if people feeling that they had a say, was all that is required from PPI.

A handful of participants recognised the need for measurements and had their own suggestions.

*“It would be interesting to do a survey of the populace and see if they felt they'd had a say.” (P23)*

*“What outcome measures can you use to see whether it is working? You could look at actual outcomes... I think that's a good marker to whether you're process is working - whether the patients are simply satisfied.” (P9)*

*“You'd have to have a standard against which to define it, really, to judge.” (P19)*

Again, Lewin's (1946) point about the need to set a measure for success is an important one. These quotes illustrate staff recognising that change should be an outcome, both in terms of how involved patients, carers and the public felt and in terms of health outcomes. The events were high profile, covered by the media and were much talked about and celebrated as harnessing the energy of a group of people and dealing well with emotionally charged issues. The activity itself was deemed successful and certainly participants believed West Norfolk was better at it than elsewhere, did more of it and made sure people knew about it. The process of involvement was seen as good practice, regardless of any impact on decision-making (Rutter et al., 2004). However, as Lewin described, a few days later, or some months on, the outcome is more unclear.

Perhaps the key issue of measuring success would also help manage the expectations of all participants (McIver, 1999), an issue described earlier.

### 6.6.2 Change yet to come

Most participants identified change that was peripheral, yet to come, would make a difference to future planning, changed the direction in which a decision might have gone or got some public ownership by being 'open'. PPI examples were given that were perceived as 'effective' or 'good examples' but do not appear to lead to direct change for patients, such as:

- Staff developed a more open style and changed the language they used to be more 'patient friendly.'
- There was ownership and understanding on the part of the patients or public of why change needed to happen or why a decision was made.
- The outcomes and responses fed into larger planning and decision-making.
- Improved learning and understanding by doctors:  
*"Doctors often think it's the procedures that worries patients - they must get the quality right - and forget that it's about the environment in which the procedure happens." (P4)*
- A change in attitude of staff commissioning or delivering health services:  
*"It certainly, I think, has changed our Board's view of the world... The service has not changed but the attitude of the people in the service has changed." (P4)*
- Improved the way staff worked, such as clinicians working better together.
- Highlighted which staff members were perceived as committed or prepared to develop their work.
- Provided information and reassurance, reducing mistrust.

- Outputs used by staff to ‘sell’ the service to the PCT commissioners.

This supports the finding from the critical document review where, out of the 46 PPI projects, only two had evidence of leading to a change in healthcare as a result of PPI.

The language used to describe or define PPI had some common trends, people giving views and ‘having a say’, influencing the PCT, raising awareness of an issue, informing people to improve understanding, addressing fears and involving people. In their definitions and descriptions of PPI, few participants directly identified the expectation that involving the public would lead to a change or improvement for patients.

*"I know the public's involved in lots of groups and things go on, but what actually happens and how much they would have a voice to change anything, I'm not sure." (P16)*

Several participants mentioned a high profile series of public conferences featured in the local media regarding the future of a community hospital, from which some services were commissioned by WNPCT, as described in Chapter 4. The hospital had been closed by a neighbouring PCT due to risks associated with patient safety. The outcome of the PPI was continued NHS closure, but supporting local people to reopen the hospital with charitable trust status. The question is whether keeping it closed was a change which led to improvements in patient care in this instance.

*"It was very important to do an effective piece of public involvement – which we did... When you manage that passion a bit more than just letting it run, actually, you've got some really positive results and some strong views coming through. And I think that demonstrated how public involvement, with that sort of education bit in it, can actually allow you to make better decisions ultimately, and that was very powerful for me in seeing how you could turn a difficult situation into a more*

*positive situation. We harnessed that passion into something where the majority of people were reasonably happy with the outcome and they accepted where we'd got to... at the moment it hasn't changed anything but it's changed the path of where it might have gone to.” (P4)*

Regarding PPI in patients' experience of a diagnostic service:

*“It was PPI in actually how it feels to have a difficult procedure done unto you... a lot of learning, a lot of understanding (by doctors).” (P5)*

Other participants described the PPI as a way of 'pacifying' the public.

*“If you get the support of the patients and of the public it's less likely to cause any hassle.” (P22)*

*“You will get far more understanding and more support for our organisation if they perceive that you're being - as the buzz words are - 'open and transparent'.... if it's clear, people will be more tolerant of what has to be done or more accepting of what has to be done.” (P12)*

*“They might not like what comes out of it at the end of the day, but at least they will understand the reasoning behind the decisions.” (P12)*

One clinician summed up:

*“We have changed at the peripheries.” (P17)*

There was an exception to the rule, reflecting the findings in the critical document review. Over a period of four years, a public conference and workshops had been held annually with the users of a specialist health service, carers, managers, doctors and other agencies. Again, this was high profile PPI activity which several participants referred to and used as an example of effective PPI where change to services were made as a result.



*“The overall thrust for X services, which we’ve tried to follow, was drawn from those conferences... It helped identify what patients really wanted, which gave it a strength and then a legitimacy to carry on through with changes against opposition from consultants and others who didn’t want those changes.... It altered the balance between public and professionals.” (P10)*

*“We were able to listen to people through experiences and we were able to reflect and make those changes.” (P11)*

When explaining to directors and managers why they should think about patient and public involvement, the Institute for Innovation and Improvement give a greater understanding of and support for change by patients and the public as the key reason (Institute for Innovation and Improvement, 2008). This, then, suggests that the changes highlighted here by participants may not be peripheral in the opinion of policy writers, but successful PPI leading to a desirable outcome.

### **6.6.3 Staff as patients and patients as people**

Participants highlighted that they were potentially a patient or had first hand experience of being a patient. They felt that that this made them change the way they treated other patients as they themselves would want to influence change if they were on the receiving end of the care or service change – a ‘do as I would be done by’ principle. This reflects Hogg’s (1999:5) explanation that “every one of us is at some time or another a patient.”

*“Nobody’s ever asked me what it was like when I was in hospital... No-one’s ever asked me and I could tell them so much about what needed to change very simply and very quickly... but nobody asks. There must be hundreds of people who use our services who could do exactly the same and who haven’t been asked.” (P1)*

*“There’s some people who are the same age or in the same position as myself.” (P7)*

*“I would want to have input on a decision important to me.” (P3)*

Several participants said that PPI activity helped them to see patients more as real people, rather than a condition. Hearing patient stories and experiences first hand was considered a powerful influence on their desire to affect change and improve patient care and patient experiences. Hearing directly from patients was seen as more powerful than reading it somewhere.

*“(PPI) can be scary - it takes you out of your comfort zone... We become so focused on what we're doing and maybe actually having a group of patients in front of you that are very passionate about something or even angry or upset, when you're not working with patients constantly it comes as a bit of an eye-opener - it makes it more real.... You get so wrapped up in the world of contractors and money that actually you forget that what you were doing it for was the patients.” (P3)*

*“It’s actually the individual experiences that people have had in the system which sticks in the mind.” (P10)*

*“It's made me more sensitive to patients as real people.” (P2)*

*“You’re hearing their story about what it’s been like for them... I think that’s extremely powerful and that’s something that I really would want to somehow be able to affect a change about. When you've actually got someone who's very sincere and who's telling you the story... It’s quite impactful.” (P7)*

One member of staff was uncomfortable with excluding patients from some decision-making, recognising that they themselves would want to have a say, if they were in that situation:

*“If we left them out... well, I would worry about what we might do or decisions that might be made... it tends to go around money and we tend to think within a certain box and patients won't think within that box, they'll think in different ways, and so we need that input and it's... it's more than that as well. It's about: we don't own this PCT or make the decisions, it's actually the public... we're not here to make presumptions as to what people want or how they want it delivered. Although, obviously there are times when we are in a better place to make the decisions, but without the input... there's something very unfair about it if you don't involve people you make decisions about... I wouldn't want – if there's an organisation making a decision about something very personal to me, I'd want to have some input.” (P3)*

## **6.7 Fear of the future**

With the PCT about to embark on a period a significant change as five PCTs were to be reconfigured into one large Norfolk-wide organisation, a question was included for participants about the ‘portability; of PPI from WNPCT into the ‘new world.’ Their responses reflected their own concerns for the future and what some had experienced historically through the days of a county-wide health authority. They expressed fears that everything would be centralised, preventing local people getting involved and that organisational change would be a priority and PPI and patient care as a whole would be lost.

### **6.7.1 Locality working lost**

Participants had a general perception that other PCTs were not so good at PPI, so merging with those PCTs would dilute the emphasis and work of PPI. However, this was a reflection on the wider concerns of the merger, where

other PCTs were seen as having a different and usually a poorer set of values and PPI was almost symbolic of the “retrograde” step of merging into a larger, more centralised, county-wide organisation, mirroring national debate .

*“I can’t see any benefits or pluses (in the reconfiguration) at the moment.” (P6)*

People expressed concern that a larger PCT would mean that PPI, which they felt should happen on a local level, would not work.

*“It depends what we’re left with at the end of the day. I think if we’re left with localities yes, but if we don’t then I think the chances of public involvement will be limited because if you’ve got a whole PCT across Norfolk and you’ve got people in Norwich managing all of it, it’s not going to work - the same as it wouldn’t work for us in our X role. If you’ve got [X posts] over in Norfolk trying to tell GPs in West Norfolk what to do - it’s not going to happen.” (P2)*

Participants talked about protecting PPI and that to do that, a locality focus would be needed, as patients would lose interest if decisions were made 20-40 miles away. They felt that if a ‘huge’ organisation, managed centrally was further away from the community, then “how are they going to know their opinions?” (P16)

Participants feared for their own service on reconfiguration:

*“So now we’ve evolved into these teams at locality level, so you can’t imagine what it would be like going back to doing it like it was.” (P2)*

*“I think one of the difficulties we have in going to one PCT is that one size does not fit all... are they going to be looking at the same sort of things across the board - the same values - across the board? If we lose that,*

*we've lost an awful lot that we've created under our PCT and I think that's one of our biggest concerns. We have lots of values here that we feel are important.” (P14)*

Responses revealed concerns from participants that principles and values might be poorer in the new organisation, fears that new management could remove the ethos of public involvement and that organisational memory (which included a memory of a commitment to PPI) could be lost.

*“If you've got a different style of leadership, then it doesn't take long to knock that kind of thing out.” (P4)*

*“I think it's really important that we don't lose those [values] in terms of when we go into the new organisation and I think that in terms of how we have worked and how we have involved the public and users, that's something that must be imbedded - must be a principle that has to be accepted as part of the reconfiguration process and it mustn't be lost.” (P8)*

*“It's about the organisational memory. I think all sorts of things will go in the changes, along with the people... where will the support be? Where will the ... PPI manager sit? Who will be there reminding them that these things are important and that they need to do this?” (P6)*

### **6.7.2 Organisational change will take priority**

Many participants recognised that during a period of organisational change, focus is inward looking, setting up new structures, recruiting to posts and finding a new identity.

*“I don't think it's going away... [but] it's something that will be lost throughout the process... It will become an even lower priority... people won't go that extra mile.” (P3)*

*“Blight for a while... It will be about 18 months before people feel that they’re in a steady state of working again.” (P19)*

*“New organisation means for 18 months there is a struggle to establish new links and risk other bits may detract from PPI.” (P10)*

*“Risks medium to high as people will take their ‘eye off the ball’ – it’s critical we don’t lose any previous work.” (P8)*

## **6.8 Enabling factors**

Barriers and solutions reflect other research in this area, as identified in the policy context, i.e., the need for more resources (both human and financial), more time, hard work, and dynamic people to lead the PPI. Clinicians cited the need for PPI research to be scientific, with a representative sample, where the results are statistically reliable. Others said they wanted PPI research to show the benefits of PPI in terms of changing patient care. Staff also identified the need to have the authority and power to make changes. Clinicians can see the need to change things, for example, the timings of a clinic, but feel they don't have the power to do it; “I have no power to change anything except in patient care.” (P17).

Critical to success was partnership working, embedding and integrating PPI into all work, but most importantly of all, ensuring change happens as a result.

## **6.9 Chapter summary**

This chapter established the extent to which the PPI policy had been put into practice within WNPCT, explored staff values and beliefs regarding involving

the public and investigated if staff believed changes had been made a result of PPI activity. From the thematic analysis of the semi-structured interviews, I identified four key themes of: PPI being important for the organisation, but not the individual; PPI being appropriate for some decisions, but not others; change resulting from PPI was peripheral; and finally, fear of the future. In addition, a brief summary of enabling factors was provided.

Staff believed the organisation valued PPI due to the prolific and high-profile nature of the activity and they themselves claimed to consider it important. However, participants were often unable to provide examples of where PPI activity had influenced planning and decision-making, with one exception. It was found that, as was reflected in the document review of Chapter 4, that there was a 'brick wall' between the PPI outputs and the outputs in terms of change in healthcare, as a result. With no measures for success identified, the quantity and profile of PPI activity was the yardstick against which participants drew their conclusions. They were unable to provide their own examples of where PPI activity had influenced planning and decision-making, other than a peripheral change.

Given the analysis above, this next chapter records the findings of the action research team meetings and examines 'bricks' in the 'wall' to aid the identification of enabling factors and attributes necessary to facilitate the breaking down of the wall.

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# CHAPTER 7: FINDINGS AND ANALYSIS

## AR MEETINGS

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### 7.1 Introduction

Chapter 2 concluded that nationally there appeared to be a ‘brick wall’ between the structure and activity of PPI and the actual change to service delivery and patient care as a result. It was shown that the DH response to this conclusion was limited in terms of only providing one-off examples of PPI activity which had led to change and not giving any insight into the **how** change as a result had been achieved, nor gave any indication about whether or how PPI was embedded in all decision-making. Ultimately, it was shown that there was no insight into how the wall could be ‘broken down’ to prevent a continuous rescaling of the wall by each NHS organisation. This left the broad research question for this thesis: **how can patient and public involvement (PPI) influence healthcare planning and decision-making?**

Chapters 5 and 6 investigated to what extent the PPI policy was put into practice in WNPCT, explored staff values and beliefs regarding involving the public and investigated if staff believed changes or improvement to patient care had been made as a result of PPI activity. The analysis of the semi-structured interviews showed that whilst the organisation and the staff purported to value and support patient and public involvement, they struggled with a unified understanding of the concept, implementing PPI was not a key priority in their own jobs, they believed that there were limits to the extent to which the public should be involved and, perhaps most significantly for this study, change resulting from PPI activity was peripheral. In addition, with the reconfiguration of primary care trusts imminent, fear of the future for their own jobs and ways of working were paramount in the minds of participants. It was evident that the



‘brick wall’ between PPI outputs and outcomes in terms of change to healthcare existed within WNPCT.

Given the analysis of the above, this chapter aims to further consider and identify what attributes and enabling factors would facilitate change as a result of PPI, to break down the ‘wall’. Tackling the issue of change and changing practice lends itself to using action research, as described in Chapter 3, with the researcher – me - as part of the change process itself. Further, it was decided to recruit to an action research team a service or team where PPI activity had taken place, but there had been little or no outcome in terms of change in service delivery or care. This enabled me as the researcher together with the participants to explore why this situation has occurred and use the action research process to identify, plan and test small changes which in turn would provide some key data for the attributes and enablers for effective PPI. Reflective diaries were maintained and form part of the analysis. This stage of the action research process is illustrated in the table below:

<b>Cycle</b>	<b>Action research stage</b>
Pre-step	Identify a general idea/thematic concern Fact-finding (reconnaissance): Document review Semi-structured interviews
<b>Cycle 1</b>	<b>AR Team meetings:</b> <b>Plan</b> <b>Act</b> <b>Observe</b> <b>Reflect</b>
<b>Cycle 2</b>	<b>Revised plan</b>

**Table 7.1: Stage of action research**

This chapter provides the analysis of the meetings and the reflective diary entries in the context of the earlier semi-structured interviews analysis and the reconfiguration of PCTs that was taking place during the period of this research. First, the AR meetings process and the project chosen by the AR

team are described. Next four key themes are identified from the analysis and finally some discussion on the researcher as insider is provided.

In analysing findings, and as with the critical document review and the semi-structure interviews, a process of thematic analysis was conducted, in which data from the action research team meetings was examined closely for key patterns and themes.

It is worth noting that by the time of the final action research meeting, participants had technically TUPE transferred to a new organisation as their predecessor PCT was reconfigured. The reality was that only directors had been secured in new roles and I was in a process of applying for a job in the new organisation whilst still maintaining my old role.

## **7.2 Recruitment to the AR team**

The method in Chapter 4 outlined the intended recruitment process to the AR team. The document review of PPI activity and outcomes in Chapter 4, specifically ‘consultation finder’, the searchable public involvement database on the internet ([www.YourNorfolkYourSay.org](http://www.YourNorfolkYourSay.org)), helped to identify the relevant team to recruit. The analysis function of the database determined which staff group had carried out the most PPI activity, but had not concluded the ‘what we did with the findings and what difference did they make’ section. One particular group of staff had carried out several pieces of PPI activity, but little or no change or improvement in patient care had been reported as a result. This staff group is not identified in order to preserve the anonymity of the participants. For the purposes of this thesis they will be called Healthcare Team.

Having made a unilateral decision about which staff group to work with, I needed to ensure that my approach to them did not result in them feeling coerced into participating. Permission to attend their staff meeting was

obtained from the director and a brief presentation was given, explaining what the study was about, what action research was and how it would be used for this next stage of the study, what the participant role might be and invited volunteers to make contact with me following the meeting. I described the 'brick wall' between PPI outputs and changes to healthcare as a result and that I wanted to examine the bricks to enable us to demolish the wall, rather than rescale every time. I was very clear in communicating that I was not coming to them as the Public Involvement Manager, but as a student, wishing to carry out research as part of a doctoral qualification. Four members of staff approached me following the meeting, agreeing to be part of the AR team and consent forms were completed. A date and time was set for the first meeting to be held at the PCT headquarters, as it was deemed most convenient by the participants in terms of their base, free parking and available meeting rooms. Consent forms were completed between May and June 2006. Three participants attended the AR meetings and are named AR1, AR2 and AR3 for the purposes of the thesis.

The action research participants needed to define what they would want their service or department to be like in terms of acting upon outputs of PPI – the "desired future state" - then identify what work is required to reach that goal (Lewin, 1997; Department of Health, 2001d). Within this context the action research was the identification of steps to get to that state and the action and reflection thereof. It was agreed that I would facilitate up to and including the beginning of the second research cycle, enabling the team to continue to work outside of this research project. I was in a facilitating role to help staff to help themselves.

After discussion and negotiation, a total of six meetings were held following the action research cycle of 'plan', 'act', 'observe', 'reflect' with a further 'plan' for the second cycle. Two of the meetings (under the 'act' part of the cycle) were held by the participants and their colleagues, within their normal staff meeting environment and the researcher was not present, at their request. The

'plan' meeting of the second cycle took place in the early weeks of the reconfiguration of the PCTs and instead of planning future action it was more of a discussion about the future, frustration and lack of power to make change.

The participants, including me, agreed to keep reflective diaries and share all the entries with me and use some of the entries to discuss as a group, when they felt it was appropriate.

### **7.3 Overview of the applied AR process**

It soon became clear that the needs and involvement of the participants and the organisational changes taking place would have an impact on my expectations of a clear set of steps of the action research of pre-step and cycles within a spiral, as described by Kemmis and McTaggart (1997).

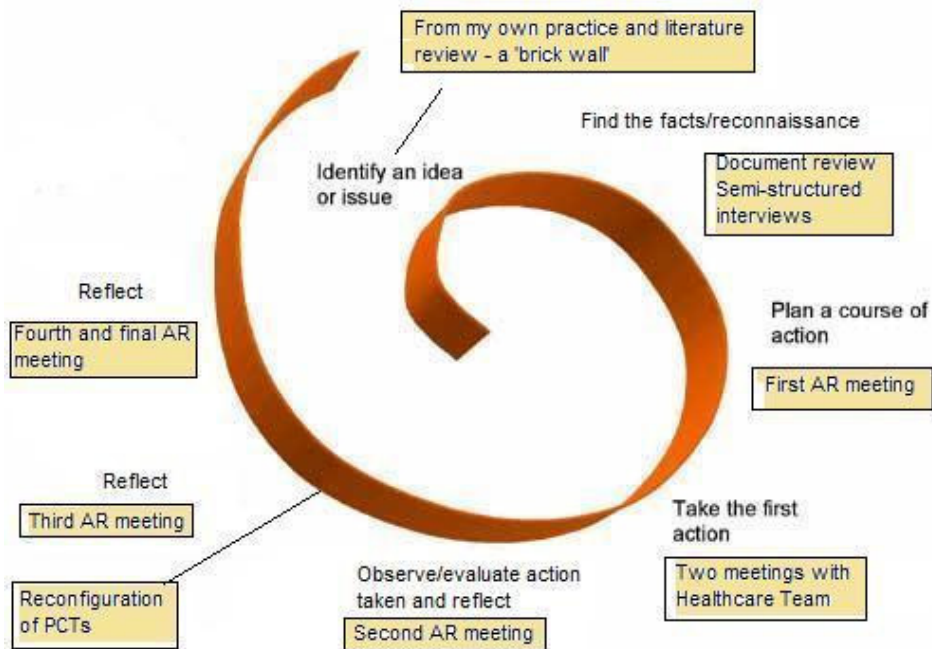
At the second AR meeting, originally intended to be an 'observe' meeting, I mistakenly introduced the session as an "analysis", having become confused with the differentiation between 'observe' and 'reflect'. The meeting was more about evaluating the action and reflecting on what had happened and the role the participants had taken in making it happen. At the fourth AR meeting I describe my confusion from the previous meeting and how it should have been 'observe' if we had strictly followed the cycle, but acknowledge that it had turned out to be a mix of observation and evaluation of the action and some reflection, which in itself had been valuable. In addition, as will be described later in Chapter 6, the reconfiguration and merger of WNPCT into a larger organisation took place on 1 October 2006 and the two AR meetings that took place following that merger were both reflection on the AR process, Project X and the reconfiguration as a whole.

In effect, the original intention to broadly follow Kemmis and McTaggart (Kemmis and McTaggart, 1997) became less cyclical and more of a continuous path, as is depicted in Table 7.2.

	<b>Action research stage</b>	<b>Action</b>	<b>Timeframe</b>	<b>No. of participants</b>
Pre-step	Identify a general idea or thematic concern	Beginning PhD Own practice Literature review	October 2003 to April 2004	-
	Reconnaissance	Semi-structured interviews	October to December 2005	25
	Fact-finding	Document review	November 2005 to March 2006	-
First action research cycle	Plan course of action	Action research meeting 1	13.07.06	3
	Take action	Two Healthcare Team meetings without the researcher	August 2006	2 plus Healthcare Team staff
	Observe/evaluate the action and reflect	Action research meeting 2	05.09.06	2
	Reflect	Action research meeting 3	26.10.06	2
Second action research cycle	Reflect	Action research meeting 4	05.12.06	2

**Table 7.2: Applied AR process**

Diagrammatically, this could be seen in Figure 7.1:



**Figure 7.1: Applied action research process (Turner after Institute for Community Learning, Undated)**

Having provided an overview of the applied AR framework, each of these steps is now taken in turn.

## 7.4 The project focus

There were six PPI projects (using the titles from the consultation finder database) where change or improvement to services as a result of the PPI activity had not been recorded. The print-outs of the project details were taken to the first action research meeting for participants to decide upon which project to focus. Again, the specific projects are not identified to preserve the anonymity of the participants.

The AR team discussed the evaluation of one particular project (Project X) at length, finally agreeing that it would be the focus for the AR meetings. They explained the background to the project where a national directive was implemented locally resulting in the replacement of clinical visits with written advice for patients. Eighteen months on, the Healthcare Team had decided to evaluate the use of the leaflet through a clinical audit. The audit involved semi-structured interviews with key health professionals and other practitioners working with the same client group. They then described how I, in my Public Involvement Manager role, became aware of the audit and had told them that they needed to include patient views:

AR1: *“You said we hadn’t taken the angle of patients.”*

AR2: *“Where’s the patient?!”*

There then followed a period of confusion where there was an expectation that the Public Involvement Manager would carry out the PPI (as the clinical audit had been carried out by the clinical audit team), but they finally went on to do a total of 12 ‘discovery interviews’ (a semi-structured interview method which allows the patient to describe their patient or carer healthcare ‘journey’), describing the process as “brilliant”, that they “loved doing it” and “it actually worked” and they heard “incredible stories”.

All participants agreed that Project X would be the focus for the action research project. It was decided that I would not attend their staff meetings, where they intended to carry out the ‘act’ part of the action research cycle, even to observe, as consent had not been obtained from the other participants. Instead, they would report back at the next AR team meeting.

## **7.5 Thematic analysis**

Four themes were identified from the analysis of the AR meetings:

1. **Lack of follow through** – participants describe competing priorities, their own capacity to do PPI, the culture of ineffective practitioner meetings and independent PPI versus no ownership.
2. **Motivation and authority** – participants explain what motivates them to do PPI, but also debate how they lack authority to make decisions – both enabling factors for PPI that influences planning and decision-making.
3. **Project management** – a key enabling factor for PPI that leads to action, project management is deemed vital to maintain momentum and see projects through to fruition.
4. **Fear of the future** – before CPLNHS, and after; a barrier to PPI that leads to change.

Each of these themes is taken in turn, providing examples of the discussions and excerpts from the reflective diaries.

## **7.6 Lack of follow through**

The AR participants observed that part of the ‘brick wall’ between the PPI activity and change or improvement in healthcare services was their own inability to see PPI projects through to fruition. They recognised they were “guilty” of not following PPI through to the end; they were good at planning the activity and implementing it, in terms of the discovery interviews, focus groups, questionnaire or focus groups, but the work then “dropped off”. As they reflected, it became apparent that this was not unique to PPI activity, but to the way of working for the staff group meetings which were “muddled” with “debate going round in circles”.



The participants described PPI work that they had started but did not have time to “see through” or “finish off” due to competing priorities, travelling and attending meetings and staff sickness. Together they described feeling guilty about this, as making anything happen as a result of input from patients seemed to take so long to progress – if anything ever happened at all.

*“I think the problem is with involving the public we start it... but sometimes it’s so long before the public get that feedback because of all these things that you’re talking about that they think we haven’t bothered, really. When it’s not that fact at all, it’s just you haven’t got round to finishing it because you haven’t had time...”*  
(AR2)

Dialogue:

AR3: *“We never get back to the ‘reflection’ bit, do we; we only do the ‘plan’?”*  
AR2: *“We do kind of half – the implement bit”*  
AR3: *“And I suppose things happen to stop the last bit.”*

They considered another public involvement project, which had the same problem of not being completed:

AR3: *“We did have some PPI in that (service) - but actually that dropped off a bit – for (Y service), weren’t we, we had the steering groups and that’s now gone, too.”*  
AR1: *“Y service”*  
AR2: *“That kind of wrapped up, so it’s no wonder the public involvement kind of dropped off, was it?”*  
AR1: *“No.”*  
AR3: *“Because we dropped off, didn’t we, really?”*

When they delved further into this, the need to have decisions signed off further up the management chain delayed implementation, as often those people, too, had competing demands on their time and paperwork often sat untouched in in-trays.

Excerpt from reflective diary:

*“I feel very responsible for PPI therefore failing (I am failing). Unable to see how you manage competing priorities... Lack of time feels like the main issue – constantly sucked into operational issues. Also, some staff have agreed to participate that don’t complete or even start work... Would be very easy to think why bother. However, I really enjoy this work; uncover some really powerful stories and evidence. I firmly believe we should involve clients.” (AR1)*

Participants debated whether a ‘grass roots’ practitioner would have the time to carry out PPI and they felt that it was the developmental role of one of the participants that had enabled her to lead the activity in this instance. One participant talks about how she would love to do PPI full time, but in reality it is only one part of an already broad role and questions “How does PPI get into such a vast agenda” (AR1).

## **7.7 Motivation and authority**

### **7.7.1 No authority to make changes**

When I asked about their motivation at the time for doing the three year questionnaire PPI on top of the audit, the participants assured me that it wasn’t because I had ‘told’ them to do it in my PIM role, but instead they wanted to do it. When I probed further, it became clear that the health and related

practitioners themselves had expressed concerns about the written information for patients for some time, but nothing had been formally recorded and they had continued to use it. They described ‘rumblings’ that patients were ‘slipping through the net’ and they themselves knew that it “wasn’t a satisfactory tool” (AR2). They had hoped that the clinical audit would give them the ammunition to make the change, describing a score of ‘seven out of ten’ in confidence that change would result from the audit:

*“Most practitioners, if you asked them, I would say that they knew this wasn’t working, so something had to change.” (AR2)*

I questioned why they needed to go through the whole process of audit and PPI to make a change if they already knew, as professionals, that it wasn’t working – furthermore, doubted it would work before it was even implemented. This appeared to provoke a realisation about their own practice:

*“Are we, as practitioners, getting so bogged down with policies and things like ‘this policy says you must send out this questionnaire’, so you do it, that we don’t really sit back and think, ‘hang on, why am I doing this?’” (AR2)*

AR2 described her realisation that she clearly knew the patient information process was not working, but had done nothing about it, despite being in a role which encourages others to change practice and influence policy. “If I learn nothing else during this process, I must remember to start practicing what I preach!” This notion of lack of power to make local decisions as they are driven nationally was reflected in Chapter 2 (Rutter et al., 2004).

In the AR meetings, the participants talked about their fear of the future and how they would lose the power to make local change within a larger organisation. This is perhaps more of a perception than a reality, as participants earlier in the AR meetings highlighted a lack of authority to bring about change

locally within WNPCT. However, three years later in 2009, a contradiction between management seeing PPI as everyone's job and clinicians feeling they lack the authority to affect change is still identified as a key barrier for effective PPI (Healthcare Commission, 2009).

My role as the PIM was a crucial one. Most of the PPI activity was, if not led by me, then supported by me to significant levels. However, the authority to make changes as a result usually resided with the appropriate head of director of service. Many of the projects were instigated by healthcare teams, with my support and the agreement of the head or director of service, if not specifically, then by implication in terms of supporting the promoted ethos of PPI in planning and decision-making. However, the authority to make decisions does not appear to be a contributing factor to projects reporting outcomes.

### **7.7.2 Independent PPI versus ownership**

The Healthcare Commission found in 2009 evidence in trusts that support the view that if clinicians themselves lead the PPI, change is likely to happen more rapidly (Healthcare Commission, 2009). This is an issue contemplated by the AR Team.

AR1 read from her reflective diary, highlighting her suggestions for a team of dedicated PPI officers. AR3 questioned if this would have been so powerful, as it would have been "one step back", with perhaps not so much ownership. They debated whether it was the passion of the delivery of the analysis – the verbatim quotes from patients – that made it so powerful. Further, that the audit of professionals alone would not be enough to make a change, as 'they' would have said there were not enough resources.

I asked if the patient views would have had the same impact if they had been the view of patients in, say, Chester, rather than West Norfolk patients. AR2 felt that, although people would have found it interesting, it would not have had

the same impact. “This is something that our patients have said; ‘we don’t like this, we don’t like the way you’re doing this’ – it brings you up short and think, ‘oh, hang on’”.

*“You know I’m a big believer of patients and public involvement and I love doing it, but...”*  
(AR1)

### **7.7.3 Competing demands**

Participants talked at length about their own time constraints and competing demands in carrying out PPI and their frustration and cynicism about imposed health policy:

*“You can get to the point where you feel: ‘oh, it’s just something else, some other bright idea that somebody in an office has just thought up.”*  
(AR2)

### **7.7.4 Lacking power to change national policy**

The AR team participants felt that an attitude of impotence was widespread amongst practitioners and that it was clear from the second ‘act meeting’ that some of the staff in the Healthcare Team was disgruntled and complaining that they would be going against national policy to make changes locally. The participants felt frustrated by this and pondered whether being involved from the beginning meant they wanted to make it work. However, they all then agreed that they were the ‘type’ to get involved, they were ‘doers’, as could be seen by their involvement in the AR work. Others do not want to get involved “and they’re the very people that will put the blocks on what you are trying to do, or they’ll find excuses why they can’t do it” (AR2).

In her diary, AR2 talks about how locally they are going “against” the national trend and how the author of the national report which introduced the abandonment of the clinical visits :

*“...missed the emotional aspects (of the service) only focussing on physical development. Perhaps we should challenge that process. I feel very energised by this whole process.”*

I asked the participants about the possibility of changing national policy with the public involvement findings and there was laughter at the suggestion. They agreed that the evidence was rich locally, but that the implications were national. They were of the opinion that they can only follow national policy and not influence it.

Following the reconfiguration, participants talked about having had the authority to make decisions in West Norfolk PCT which they had then lost in the new larger PCT, however this contradicts their early remarks that they needed the patient evidence rather than just their own professional experience, to make changes in their previous organisation. However, reconfiguration disempowering practitioners from making local decisions has been recognised as a key issue, with clinicians noted as feeling unable to influence policy (Rutter et al., 2004).

### **7.7.5 Patient views provide authority**

AR1 described how using change management techniques had previously caused her some apprehension. This time, she felt more “resilient” because she had the authority from patients, as a core value of the NHS is to deliver services that are responsive to need. She believed that the DH had told her, via PPI

legislation and other policy, that she had to listen and respond to patients and that is what she had done.

The AR Team reflected on the progress of Project X and how it had continued to move on, again recognising that it was patients giving the authority to push it forward. In addition, they agreed that it was because they had the ‘evidence’ from the parents that put them in a position with which the rest of the staff team could not argue:

*“I think having evidence. That’s the strongest part. We never do start with the evidence do we? We will, as you were saying, we always start with the problem and only do that assessment and you try and find some evidence to support, whereas having the evidence first...” (AR3)*

I asked if their manager championed PPI, as within my PIM role, as I had not had dealings with that person. It transpired that AR1 was the driving force, having taken up my PPI training opportunities and being interested in it: “it immediately grabbed me.” Her line manager was “empowering” and had allowed her to take an interest with PPI written into her job description as part of her ‘innovation’ role.

## **7.8 Follow through via project management**

Through their own observations and experience via the AR meetings, participants felt the key finding, the primary ‘enabler’ of PPI that leads to a change in service or impact on policy, was follow through via project management, with robust planning, clear outcomes, tasks and timescales.

Participants expressed excitement at the pace that the project was moving forward. They described how the first ‘act’ meeting was to discover what they

were going to change and how and expressed their surprise and delight that the meeting they had held was so different to their regular staff team meetings.

*“I’m amazed at how it’s moved on because, as I said at the beginning, normally (Healthcare Team practitioner) meetings just sit and discuss one issue for the whole two hours and nobody gets anywhere.” (AR2)*

*“I have to say, I’m quite excited about this change... I can’t wait to go back now!” (AR3)*

Participants explained how they had set a timeframe, delegated tasks, managed the meeting and were clear in their decision-making. They identified ‘six ideas’ - not only to change Project X, but a further linked project as well. One of the participants had gone away and redrafted all the paperwork and they had met just the day before to agree how they were going to implement it.

I asked them why this meeting felt so different and one of the participants explained that they had used ‘logic modelling’, which was based on examples of problem-solving projects done across the county identifying outcomes and linking actions to achieve the outcomes. Another participant felt that using that process might have contributed, but she felt that being in the action research study made them more focussed, partly because I would ask them about their progress at the next meeting. AR1 reflected that there was a need to utilise the discipline of project management, with the associated Gantt charts and time lines, for public involvement, to ensure that “things don’t drift”.

Participants described how being involved in the AR process helped them to keep momentum on not just the three-year check project, but also on marketing their own services in the new reconfigured PCT, particularly with a significant financial deficit. No participants observed that perhaps the staff meetings were different because of their own approach to them; their challenging and positive behaviour, and staying focussed.



Extrapolating on the need for project management and removing the conflict of competing priorities, one participant proposed a dedicated PPI project team, with the time to give to PPI, who would not be biased as they would not be delivering the service being examined:

*“If the Government are really committed to PPI, perhaps they should introduce dedicated teams to manage it... We have an audit department (or did have!), just to deliver audit, HR team just for HR. In our PCT we have one dedicated person – Trish – for PPI. Surely this smacks of tokenism in itself?” (AR1)*

Regarding the project, participants had been told by their manager ‘continue until you are told otherwise’, so despite the reconfiguration and financial turnaround, they had implemented their new pilot for Project X with a Healthcare Team practitioner and also that the staff teams had fed back on the six tasks they had agreed. One of their key findings of this was that there was only about 40% uptake on the offer to have a clinical visit. Having delivered what the patients had asked for and then found the uptake so low; I asked if that made them question the validity of the discovery interviews.

*“But that fits really nicely into the action research title, doesn’t it, because what we’ll do is we’ll do the pilot bit and get the evidence, reflect on what we’ve got from that and then we’ll look at what we’re going to plan for the next bit... So in some ways, it’s actually really quite nice, isn’t it? It’s been really good.” (AR2)*

AR2 described how well the staff meeting had gone; calling it a “miracle” when normally they “go round in circles debating everything”. She talked of how the AR team members had challenged negativity in the group, set timescales “which I am really pleased about, as it drives me mad when things just drag on getting nowhere fast.”

At the second ‘act’ staff meeting, this participant felt:

*“Everything about this project has been more positive and plans have moved on rapidly. I can’t decided why that should be – is it the action research focus making those participants move things on? Or is it because the (patients) have indentified this is what they want?” (AR2)*

Participants highlighted that they had never before had the opportunity to talk through with someone and reflect on the public involvement they were carrying out, saying it is:

*“almost supervision... I think that’s what people need; that support with it, because it’s managing change, isn’t it, that’s what you’re doing.” (AR1)*

## **7.9 Fear of the future**

The participants expressed concern about where PPI would ‘sit’ within the structures of the new PCT and that the new organisation would only be paying lip-services to PPI, which would in turn mean that the evidence from the discovery interviews would be ignored.

Participants talked about discovery interviews being a way of ‘breaking down the brick wall’ between public involvement activity and change in healthcare, as their experience on the three-year check had been a powerful stimulation for change. They were concerned that the new PCT would not deem PPI important enough and would therefore only do more quantitative activity, such as “occasional” questionnaires and audits, which was less time and resource consuming. The new focus was on business and money so; “How do you make them boys there believe that piece of quality work will save money?” (AR1).

Participants discussed the benefits and drawbacks of quantitative versus qualitative PPI research. They felt that quantitative research was deemed more credible and furthermore, the changes made as a response to PPI were often not quickly seen, nor measurable.

*“Generally it’s hard to feel energised about anything at the moment given PCT reconfiguration, huge deficit, uncertainty about our futures. A ‘why bother’ mentality is inevitable, yet we have to fight the inertia and keep the momentum going.” (AR1)*

In her reflective diary, the same participant describes how the pace of change due to the reconfiguration has slowed the pace of change on the three-year project.

*“I’m left feeling I should have been better at getting things done faster. I feel more than ever NHS is widening the gap between rhetoric and reality. Nothing seems to make sense any more... difficult to see any meaningful future.” (AR1)*

Their major concern was seeing this work through to evaluation and feedback to patients, if their own jobs had changed to such a degree that they were not around to do it, both in terms of the job not existing and in terms of someone new doing the job who was not interested in following the project through.

Participants also expressed concerns that they had lost the authority to make decisions locally and that they would be told to “cut” the project. They had fed back to a wider county meeting of Healthcare Team professionals who said they did not recognise that there was a problem with Project X. AR1 had taken the evidence of the discovery interviews, but because they felt it didn’t reflect their own experiences, it was unlikely to carry on. AR1 said she was angry and used the analogy of a “motorway” she could not get off. They agreed that, due to the reconfiguration and the state of the finances, they would no longer have

the same influence on services and local policy, that everything would be centralised and local ways of working and local autonomy would be lost.

## **7.10 Chapter summary**

To conclude, this chapter has shown how the AR participants recognised that they themselves were part of the ‘brick wall’ between PPI activity and change to services as a result, as they would terminate once the PPI activity had been implemented. They cited competing demands, loss of authority to make decisions and lack of project management as reasons for this, but their participation in the action research ensured structure, timeframes and outcomes to their PPI project which meant that changes were made, albeit halted once more by a reconfiguration.

Participants described how patient views empowered them to feel they had the authority to implement change in health services as a result of PPI. They also discussed how the patient voice motivated them to want to make changes, but how this was diluted by not having direct involvement in the PPI activity. Moreover, a key barrier was the competing demands on them as practitioners which meant that the momentum halted and implementing change as a result of PPI did not take place.

Having identified the research issue and gaps in knowledge, provided a critical document review and provided a thematic analysis of the semi-structured interviews and the AR team meetings, this next chapter on reflexivity explores my own insights into my own practice throughout this process. I reflect on my personal subjectivity towards the research issue, my struggles and epiphanies and record my own growth and development throughout the study.

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## CHAPTER 8: REFLEXIVITY

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### 8.1 Introduction

In the previous chapters I provided the findings and a critical analysis of the data from the document review, semi-structured interviews and the action research meetings. This chapter provides an opportunity for me to reflect on my journey through the research process, beginning with my initial subjectivity and prejudices, through to the learning and growth I experienced both as a researcher and a practitioner. It is argued that reflexivity is an essential element of any qualitative study (Kuper et al., 2008) and from commencement of my PhD I maintained a journal, part practical in terms of keeping notes from my meetings with supervisors and part ‘state of mind’ and reflections on the process, my supervision, my struggles and dilemmas with the research, the analysis and writing the thesis. I used ‘smiley’ cartoons of myself to depict my state of mind following meetings and periods of study. This reflexivity is provided in the form of a narrative account, befitting the process of expressing my own views, observations and critical thinking.

### 8.2 My prejudice and subjectivity

I came to develop my inquiry with the belief that if my organisation, West Norfolk PCT, was nationally and locally perceived to be one of the best at PPI that led to change, and we had helped tell others how to do successful PPI via the legislation guidance and examples of best practice published nationally, then there was something significant and unique about WNPCT that made it work. I believed that if I could identify and demonstrate what this was, then I would have a ‘toolkit’ to allow others to be as good.

Being the Public Involvement Manager (PIM) at the time of the research meant that I was an ‘insider researcher’ as discussed in Chapters 3 and 4. My insiderness affected the research method, the initial research questions, the interview questions, the way I asked them, whether I probed or took it as read (due to my insider knowledge), how the participants responded to me, and in the themes and patterns for which I searched. Any subjectivity came from my strong commitment to ensuring the PCT listened and responded to the views, needs and wants of the patients and public with whom I had engaged in PPI activity.

My formal periods of learning for my doctoral study were ad-hoc snatched periods of study leave during a time of significant change and upheaval; securing a job in the reconfigured PCT, then proving myself, endeavouring to ensure that the omens from the interview participants did not come true and then a further promotion to Director. There was a 12 month period where no study took place at all and my research was put on hold. Rather than the traditional ‘reading – research – writing up’ structure, I followed a more meandering course of reading – writing – research – research - research – writing – writing – reading – writing, with each element occurring during a brief few days of study leave, usually months apart and with fresh eyes at each step.

When I originally analysed the semi-structured interviews I felt positive and even vindicated. Here was everyone talking about PPI, citing some of my major, high profile and successful PPI activities and I felt I had obtained what I set out to prove – qualitative evidence that PPI was working in West Norfolk and I had done a good job. However, with a two to three year gap since that original assessment, I was in a new job with a team of staff doing PPI in a new organisation and I saw the raw data very differently.

My initial subjectivity towards the ‘expertise’ of West Norfolk in implementing successful PPI that resulted in change had led me to a prejudiced and non-

judgemental, non-analytical document review. I took the documents at face value, producing an uncritical chronology. Only in writing up the analysis some three years later after the original document review – and with the removal of the ‘blinkers’ in terms of my re-evaluation of the semi-structured interviews and the evidence of the PPI activity in the action research meetings – did I realise I had made incorrect and unchallenged assumptions. This caused me to self-evaluate and acknowledge my mistakes in understanding.

It was like a veil had been lifted and my findings were now very different to how I had perceived them. Rather than confirmation of a job well done, I saw some negativity and ambiguity. As I read the transcripts, I questioned what I had always believed to be the commitment of the organisation and instead began to query if it was more rhetoric and a political tool. I was able to shake off the loyalty to my previous organisation and the person I was then, trying so hard to prove herself under threat of redundancy. Instead, I was able to bring more objectivity, analyse the data in different ways to how it had been presented and synthesise this into a new picture of PPI in West Norfolk.

Somewhere along the line the question changed from “How can I show others how to do PPI that influences planning and decision-making, learning from my success in WNPCT” to “How can I improve my practice of PPI and that of others from the action research learning in West Norfolk”. Would another researcher have got the same results and arrived at the same conclusions? What if they, too, were the PIM within their organisation?

The benefits of my insiderness, in terms of the research, were that I had an intimate knowledge of the context of the research and of the micro-politics of the organisation and participants were easily reached. On the negative side, the close contact with my organisation and colleagues made objectivity difficult to attain.

When one of the AR participants explained that a project had been delayed because she thought I would be leading on the work I had two key thoughts around her comment. The first was me as 'PIM', with a clear understanding in my own mind from the period of time we were discussing, that it was always for that staff group themselves to do the work: how was I, just one person with a remit for ensuring PPI across the whole organisation, actually implement all the activity on my own? It is clear from the semi-structured interviews that the AR participant was not alone in her belief, as 'that's Trish's job' was a key message from staff at the head of the organisation. I had become synonymous with PPI, which ultimately meant in everyone's eyes that I did it all. It appeared that the message that PPI was important had permeated the organisation at all levels, but the concept that it was 'everyone's' job had not.

The second feeling was one of guilt – guilt that I hadn't guided this member of staff sufficiently, guilt that I had done nothing to ensure the projects were implemented. That initial feeling became recognition of my own role as PIM in the success or failure of enabling change to result from PPI. Within my own organisation, one of the most prolific in terms of churning out PPI activity, there was a brick wall between the activity and change in health services as a result and I should have spotted this and done something to resolve the issue. Instead, I rested on my laurels, content with the accolades from my own Board and from the national recognition.

In the previous chapter, I described a resonance with Lewin's (1946:35) description of a change leader with no formal "criteria for evaluating the relationship between effort and achievement" believing the congratulations of colleagues to be that measurement of success. Lewin uses the analogy of a captain of a ship correcting an over steer which then leaves his vessel turning in circles, whilst he goes to dinner confident that he has ensured the rudder has made the appropriate movement. This aptly describes my own experience, with the benefit of hindsight. My observations were made from 'within the boat'; as leader of my own 'ship' I had taken all the right actions, put in a huge amount



of effort and everyone was telling me I had done a great job. However, with the benefits of this study I am able to take a more objective look back and see that, though maybe not going round in circles, I had no criteria for evaluating a successful outcome in terms of change to health service and therefore no way of measuring my success. But then I must question if I **was** the captain, the member of staff with the authority and accountability to set the course, or should it have been the director in charge of the portfolio, the Chief Executive, or maybe even the Board. I provide no conclusion on this, just the slight salve to my conscience and an appreciation of what I must do in my new organisation to not repeat the mistakes of the past – as this time I am definitely the captain of the ship, as the director lead and a member of the Board.

This became an understanding that project management and embedding PPI in the decision-making process of the organisation was critical. Those with the authority and power to make decisions based on the feedback from patient views need to (a) formally decide and agree the extent to which PPI will be used to shape any decisions and (b) performance and project manage the process right the way through, with PPI output reports coming back to those decision-makers to discuss and formally agree how they have influenced the planning and decision-making.

### **8.3 Improving my own practice**

I used this understanding of project management in my new organisation, putting in place a robust formal mechanism whereby any PPI has to be agreed by the commissioners, the PPI output reports return to the commissioners to discuss and agree how they will be used to shape the outcomes, balanced with clinical effectiveness and value for money. In addition, the commissioner is then required to take that final change as a result of PPI (and other factors) to the Board. I have asked the Board to champion PPI as part of their performance management, to ensure they ask the questions: ‘where is the PPI in this and how was it used?’

A significant enabler to PPI is the need for it to be project managed and overseen from concept agreement by the commissioner through to the decision-making process and feedback to participants on how their views and opinions have been used. In my new organisation, I have set up a team responsible for just that. They are part of every commissioning process and decision-making group. They challenge for the need for PPI in planning and decision-making, if not automatically considered, then bring the research proposal to the group, and obtain ratification, agreement on how any outputs will be used and ownership. Once the research is complete, the outputs report is taken back to the group to decide how it influences the planning or decision-making. The commissioners take the results of this (which might be a revised strategy, or a change in service delivery, a new care pathway, or a tender document, for example) to the Board. The commissioner also agrees a 'you said, we did' document to go to participants that demonstrates the changes made as a result of their input.

Instead of doing PPI in-house, where it is one person's job, my PPI team now commission PPI activity via an independent research company. The proposal must demonstrate a robust research method, appropriate for the target audience(s) and relevant for the 'research' question. Again, this has taken into account the learning from the semi-structured interviews where participants seek a more scientific, less subjective, approach to obtaining PPI views. The research company have to provide evidence of high quality analysis and the confidence levels for each PPI activity. They produce a report that is quality assured with recommendations highlighted as a result of the outputs. Justification for the research method is always given, together with the limitations and risks for each, which is ratified by the commissioners of the relevant healthcare service. The PPI team oversee the entire process – it's their 'job', but the accountability has been integrated into the commissioning cycle.

I have also shared my learning on this at a national policy level, as described earlier. The most recent legislation guidance is partly based on my own

research observations (DH Commissioning and System Management - PPE, 2008). There is now a requirement for PCTs to produce an annual report that provides a synopsis of all the PPI activity and how each one has influenced decision-making and this will hopefully provide further impetus. Conversely, it could also lead to consultation only taking place when the direction of travel is one the decision-makers already intend to take.

The new skill of critical thinking that I have obtained through this research process has been vital and, in part, enabled my promotion to full director level on the Board of my new organisation. However, it would be easy to become complacent and repeat the errors of the past, as once again I am proud that my organisation is perceived to be leading edge and we are winning awards for our PPI work. I must continue to use this critical thinking and encourage my PPI team to do so. We need to continuously evaluate the effectiveness of what we are doing: can we really demonstrate that patient and public involvement has enabled change as a result?

In my own journal reflections of the first meeting, I describe my nervousness about the meeting, having never had an action research meeting before. I talk about my confusion regarding methods for implementing action research in health from what I have read. The literature points to a range of techniques from focus groups through to observation and if it “appeared event remotely participative, it was called AR”, informal and unstructured.

I also expressed concerns about achieving a balance between researcher/practitioner and whether I would lead, direct or coerce the group for my own needs or to my own end. I was also worried I would “push them too hard” due to my own PhD time constraints, due to the potential for funding to be withdrawn following reconfiguration. I noted in my reflective journal:

*“I was on a high when I came out of the first meeting. It was so inspiring! They picked something to look at and a meeting was already*

*arranged, so I knew it would progress at a pace.”*  
(Reflexive journal entry dated 13.07.06)

One meeting began by following up a question I had been asked before the recorder was turned on: ‘why did you do so much talking then at the last meeting’ (I had previously expressed concerns that I had talked too much). I explained that in research the researcher is often not directly associated or employed by the organisation, but in my case I was an ‘insider researcher’. At the first two meetings I had ‘sat back’, but by the third one I told the participants:

*“I’d got so interested that actually I really wanted to explore some of the things I’d thought with the people that were here – otherwise they were just my thoughts and I never test them out and I never ask whether I was on the right track or not. So I think a lot of it was me coming up with some of the ‘this was some of the thinking I’d had’ and that’s why I talked so much.”*  
(Reflexive journal entry dated 26.10.06)

## **8.4 Considering methodology**

The idea for using AR as my methodology first came as a suggestion by my then primary supervisor at one of my first meetings with him in October 2003. The journal entry I made at that time (October 2003) records that I wanted to take further my interest in patient and public involvement leading to change in healthcare services in my own organisation. As described in Chapter 1, I had a work interest in the subject, but had also written a dissertation on the subject for my first degree just a few months earlier. My supervisor briefly explained what action research was and how it appeared to fit with what I wanted to do. Upon his recommendation I spoke to another secondary supervisor in depth who was very clear that AR was a clear-cut, step-by-step process that should be

followed. Not having carried out any academic research previously, action research appeared to be a strong, rigid framework for my first attempt. It felt reassuringly scientific and academic. At the same time, the methods I intended to use – semi-structured interviews followed by facilitated ‘focus’ groups – fitted both my training and my experience.

My journal entry dated 6 December 2004 recounts the verbal feedback I had received from my secondary supervisor at the time following receipt of my first draft of my thesis. He acknowledged that the writing was in a ‘stream of consciousness’ state, but made it very clear that I was to remove all mention of my job, ‘I’ or ‘my’, as this was inappropriate for a research study and that I was not unambiguous enough in the steps I planned to take.

Just over a year later (22.03.06), my journal records me experiencing an “epiphany moment” after meeting with my new secondary supervisor and being told it was imperative to put the ‘me’ back into my thesis.

Action research is far ‘messier’ than I had originally understood, an issue that is noted by many action researchers (Morton-Cooper, 2000; McNiff et al., 2003) and this is noted in my methodology section where I start off following one particular AR process and end up with more of a ‘journey.’ In addition my research question changed, as I gained more insight into my own practice and was able to provide some critical distance from my findings. Whitehead and McNiff (2006) talk of theories that constantly change and need revising. Had I retained my first cut of my analysis of the semi-structured interviews, my theory would have been very different to the one I decided upon. Is either theory right or wrong, or just different, or are they both right, even as they contradict each other. One was a knowledge claim at the time, potentially just as valid as the claim that came later. Epistemologically, I create a knowledge claim, a truth – my understanding filtered through my own insights, perception, upbringing, experience, values and beliefs – I make a “knowledge claim” (Whitehead and McNiff, 2006).

I was clear that resulting from this study that:

*“the knowledge, information, tools and other produces will have a high probability of being integrated into policies, planning approaches, practices and standards ranging from strategic through to operational”* (excerpt from reflexive research journal November 2003).

McNiff and Whitehead argue that an action researcher is an insider researcher and by definition cannot be a mere spectator. They say the focus for action researchers is on the question ‘how do I understand, develop, influence, improve?’ (McNiff and Whitehead, 2006) and claim that some action researchers make the common mistake of watching other people do action research and asking ‘what are they doing?’ rather than recognising their own role in AR. To some degree, although I was running the action research process – organising the meetings, taking the ‘minutes’ – I believed I was watching what they did in their practice at that point. Initially, I did not see myself as part of the situation in the AR meetings specifically. Instead I thought they would study their actions and they would be part of my data. Only with the benefit of hindsight was I able to see my own role in their action, and how I was equally involved in reflecting on my own practice and taking action as a result since.

Mention is made of a blurring of roles between the AR project and the research project required for an academic qualification, such as a doctorate (Coghlan and Brannick, 2003), again, a particularly pertinent issue for my own role as researcher and doctoral student. Throughout my PhD journey I was keen that anything I produced would have a practical application and would hopefully produce a toolkit to enable me and others practitioners to improve practice. In addition, I found that as I carried out my work as the Public Involvement Manager, and more latterly as the director in charge of a team of PPI managers,

I have been very aware of the need to complete my doctorate to enable me to continue with my career progression and I have retained information, thoughts and documents that would be of interest in my study. This blurring of roles has at times felt like I have lived and breathed the project, both as a practitioner or researcher, for seven years.

## **8.5 Chapter summary**

In this chapter I have provided a narrative account of my assumptions and experience that may have shaped and influenced this study. I have explored my prejudice and subjectivity, my learning in terms of improving my own practice, and provided reflection on the methodology and conceptual framework used for this study. Seven years have passed from the beginning of my doctoral journey to the conclusion of my thesis and I have plotted my journey, both physically in terms of the ‘chunks’ of study, separated by long periods of work, and mentally, by reflecting on my personal growth throughout that period.

I have learned so much about myself, the assumptions I make, how to look beyond the obvious and the impact I have on others, both as a researcher and as a practitioner. I have loved every moment of it!

In this next chapter, I draw conclusions about the research question, make recommendations for research, policy and practice, identify the contribution I have made to new knowledge and highlight the potential limitations of the study and opportunities for further research.

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## CHAPTER 9: DISCUSSION

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### 9.1 Introduction

This study investigated patient and public involvement (PPI) in the NHS and explored the question: how can PPI influence healthcare planning and decision-making? In my thesis I set out the national policy context for the study. I then justified the chosen research methodology and methods. Next, I provided the findings and thematic analysis of the document review, semi-structured interviews and the action research team meetings, followed by a reflexivity chapter. This chapter summarises the conclusions made, specifies the contribution made to new knowledge and highlights the implication for theory, policy and practice, before describing the limitations of the study and making recommendations for further research.

### 9.2 Conclusions about the research question

In AR, participants evaluate themselves individually and collectively (McNiff and Whitehead, 2006), however, Lewin's (1946) example of the minority speech event poses the question of whether is it possible for an insider to set the measure against which to evaluate. Lewin argued that if you are observing yourself and your own actions, it can be difficult to be sure the right measurement or criteria are being used.

In the case of the healthcare workers in this study, the root cause of the problem they chose for the AR project was that patients were developing major problems at a later date that could have been avoided had the issues been identified and resolved through an earlier intervention. Anecdotal accounts



from healthcare workers and partners agreed that this was an issue as did the patients when asked subsequently. The action taken was to reintroduce the intervention and the measure of success they set for the AR project was the number of patients taking up the offer of an early intervention. However, the uptake was poor and it calls into question whether it was the right measurement, or would it have been better to measure the healthcare issues that 'slip through the net'.

With objective criteria regarding the movement towards an agreed desired outcome, success can be measured (Lewin, 1946). Lewin purports that following the framework of an action research cycle will bring about change with people cooperating in an open and transparent way to identify issues and solutions to change the situation. It is possible to associate his illustrations of the cycles in action with examples that might be provided today of effective patient and public involvement. Therefore the potential to use action research as a model for the process of PPI must be considered. Indeed in a discussion of the dual role of the action researcher, Trondsen and Sandaunet (2009) noted that the cyclical basis of the meetings provided more leadership and structure to the management of programmes of work. Hall (Hall, 2006) agreed that professionalising action research could be a way of bringing about change in health services, whilst noting that the reflective element required may prove difficult to secure from all participants.

The same debate around measures of success around what denotes 'good' PPI applies to the question of the award of 'beacon status' to West Norfolk PCT. It was shown in the document review in Chapter 5.4 that WNPCT won national awards, was cited in several DH documents as a beacon of good practice and was contacted by several other organisations for support and guidance. However, once again, the measure of success was based on the prolific PPI activity, rather than on the impact on healthcare planning and decision-making. In its defense, at the time of the data collection in 2004-5, WNPCT was one of the few PCTs that were able to demonstrate that PPI activity took place,

regardless of change as a result. It can therefore be argued that the best practice status that WNPCT held was warranted as an example of prolific and systematic PPI activity.

In chapters 4 and 5, one programme of PPI was identified as being an exception to the rule of peripheral change, as both the document review and participants in the semi-structured interviews were able to cite what changes had happened as a result of the PPI activity. Exploring this further, I have produced two vignettes, where this project, Example 1, is contrasted with Example 2, where there were no reported outcomes following the PPI in a diagnostic service.

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**Vignette: Example 1**

The Director of service identified the issue and together, working with a project group, we planned an initial all-day conference with numerous workshops with the aim of asking what was good, what was not so good and where the perceived gaps in the current service were, and to produce a prioritised action plan for service improvement. Over 100 participants attended, which included patients, carers, staff, managers, clinicians, providers and interested parties. At the end of day, the conference was evaluated in terms of participant's satisfaction with their involvement and I carried out a thematic analysis, producing a report for the project group. These themes comprised of a 'wish list', as identified by the participants themselves. Using the list, a draft service specification was drawn up and a further plan of action led to another conference where the specification was 'tested' with the same participants from the initial conference to check we had correctly assessed their needs from the list. They broadly agreed, with some amends.

Another evaluation and another analysis report provided resulted in changes to the specification and the content was put into action. The following year, a further conference checked back with participants, asking, how it felt to be on the receiving end of the newly revised services. The participants were able to

tick off some actions from the list, but all agreed that ‘wish list’ was no longer the correct term – it was now a set of expectations.

Again, amendments were made to the service, further actions taken and there was an annual revisit to the original questions of what was good, not so good and where were the perceived gaps in the now revised service. More actions were ticked off from the ‘expectation’ list.

In the final year, the service users themselves led the conference, highlighting and celebrating all the actions and changes that had taken place over the four years, culminating in all the actions off the list being completed. Throughout the period, effective use was made of promoting the service to staff and via the media.

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**Vignette: Example 2**

The Director of service identified the issue of needing to obtain the experience of patients using a specific diagnostic service, so that appropriate changes could be made. Working with a project group, I planned the PPI activity, which in this instance was a method of questionnaires to be given to patients over a given period at all the healthcare settings where the diagnostic procedure took place.

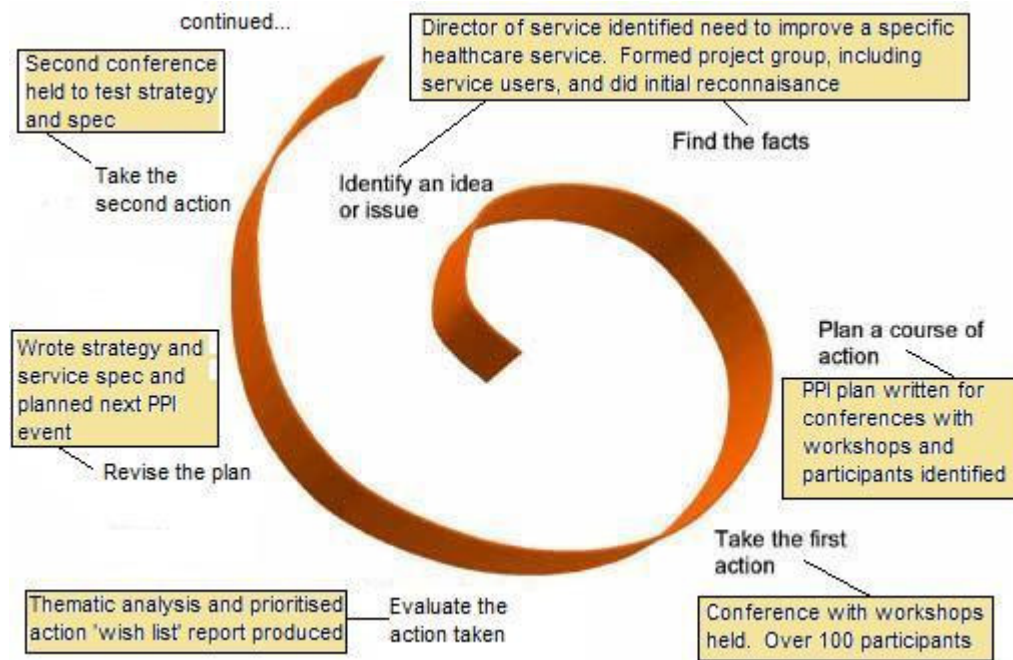
Upon receipt of several hundred questionnaires, I produced a themed analysis report which I submitted to the project group. The paper also went to the Board who congratulated the group for their work.

There is no outcome reported, other than the feedback from the semi-structured interviews, where this was cited as an example of effective PPI in terms of clinicians recognising that patients have fears and are not just a condition.

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In both these examples, the initial measure of success was to gain patient views to determine future action. In the first example, there then followed a cycle of

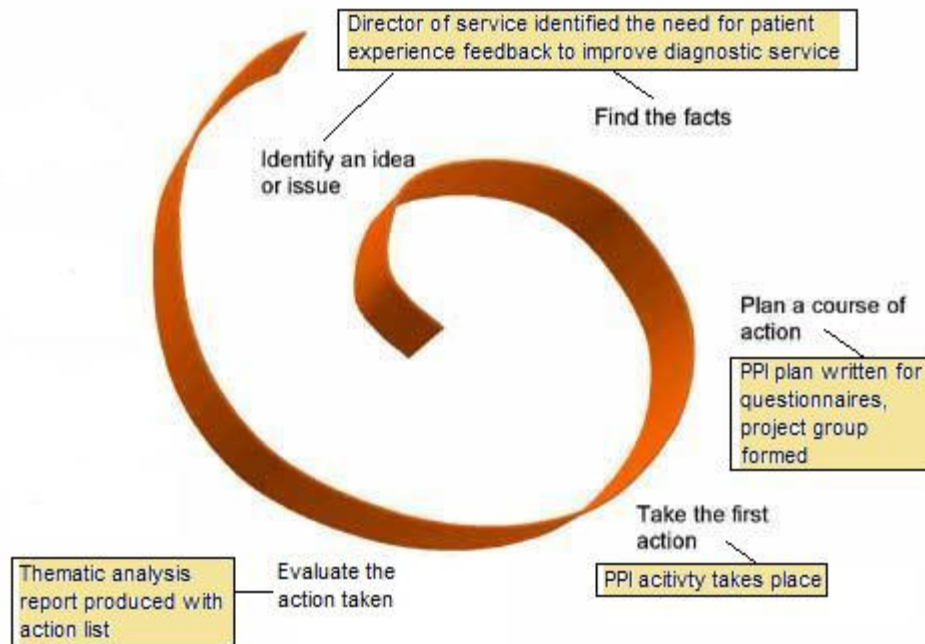
project management, inadvertently following Lewin's action research cycle, as depicted below:



**Figure 9.1: Vignette – Example 1**

It can be seen that the process of setting measures of success and continually revising them following through a process of action research project management, changes were made to healthcare as a direct result. Studies have found that the only instances of PPI leading to change was where that change was already identified by the decision-makers as the preferred direction of travel (Rutter et al., 2004), however there is no evidence that this is the case here. Instead, the document review clearly indicates that the actions were drawn up through the PPI process directly from participants – and in particular users of the service, as they had their own workshops in the conferences. In addition, the participants in the semi-structured interviews cite this example as one where the views of patients provided the direction of travel.

Using Lewin's action research cycle, Example 2 can be depicted thus:



**Figure 9.2: Vignette – Example 2**

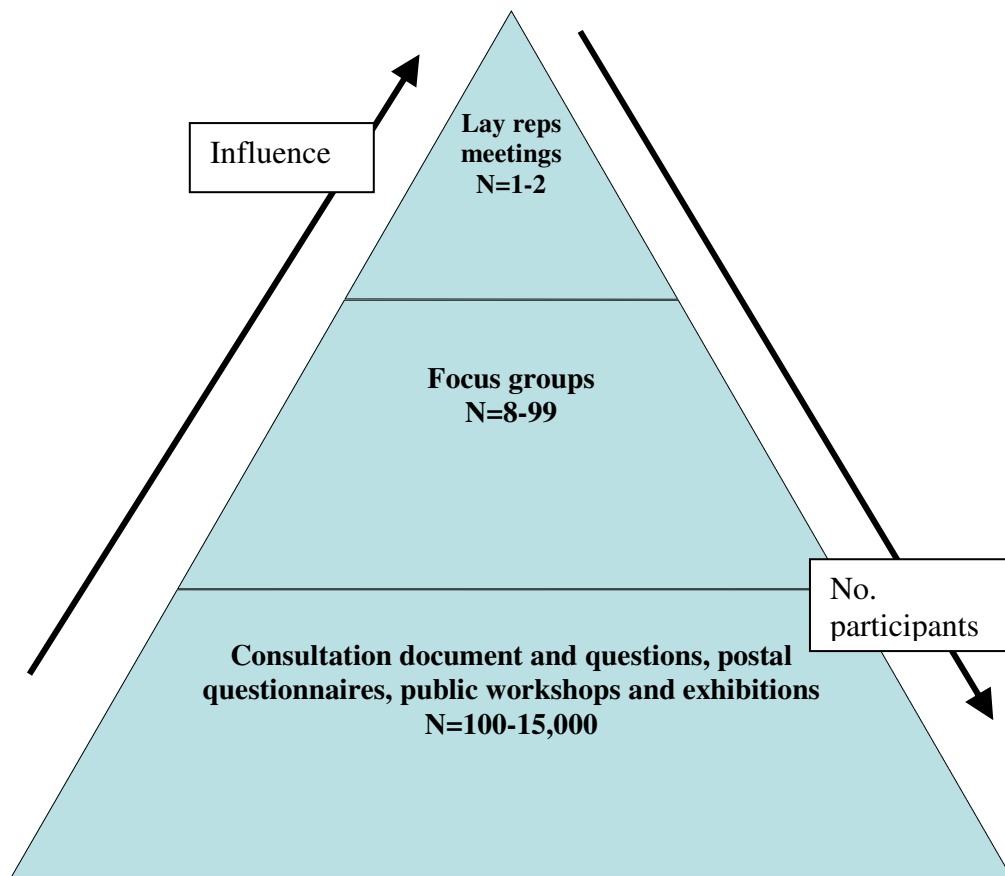
It is clear from this diagram that there was no follow through after the initial action. There is no evidence of a revised plan where actions (measures of success) were identified to make changes to the diagnostic service as a result of the PPI. This is a similar story to that of the project identified for the AR team meetings. It had reached the same point as Example 2, until it was looked at as part of the AR project, when a revised plan for action was made at AR meeting 1, meetings 2 and 3 were ‘act’ meetings, continuing on the action research spiral.

Rutter et al., (2004:1977) identified a failure of organisations to integrate PPI feedback into planning and decision-making. They quote one worker; “in

theory, all we should have to do is raise issues from users, take it to the appropriate provider, explain why, and leave them to sort it out. In practice, it's a huge negotiation process... if we back off, they carry on as before." This indicates a lack of 'ownership' by those with the authority to make decisions. Possibly, they needed to have been involved in setting the measures for successful involvement. It also reflects my own practice, illustrated with the healthcare groups that formed the AR team. Without my encouragement they agree that they would not have involved service users and without the AR project, they may never have followed through with the response to user feedback.

In Chapter 2, models of participation were summarised. This study has shown that regardless of model, typology or technique used, if there is no process for agreeing parameters and measures of success, receiving the analysis of the feedback and making decisions based on that analysis, then PPI will have no influence on planning and decision-making. It therefore follows that the power to influence change lies with those who receive the analysis and make the decisions based on that analysis. If there is a process in place - a cycle of steps as illustrated in the model proposed here - that ensures the analysis is considered and acted upon, then it follows that PPI is at least on the agenda with the potential to influence planning and decision-making. The over-riding finding remains, however, that the power, and therefore the influence, remains with the organisation/manager rather than the individual or community group with whom the organisation engaged.

The experience of staff of the involvement of lay representatives at meetings can have a detrimental affect on the willingness of staff to involve patients and the public, as was found in Chapter 6. To help explore this further, figure 9.3 illustrates a pyramid model for the levels of patient and public involvement in the planning and decision-making process of NHS healthcare commissioning.



**Figure 9.3: Triangle of involvement**

At level 3 there are the largest number of participants giving their opinions on a proposal or plan, such as a proposed new care pathway for eating disorders, the co-location of a specific service or a new strategy for caring for patients with dementia. The method of involvement might be a consultation document with related questions, a postal questionnaire, or a series of public workshops. The sample might include those currently using services and their carers, stakeholders, relevant third sector voluntary and community groups, health and social care partners and interested parties. The numbers involved at this level are typically around 100 – 15,000.

Level 2 might include relevant patient or community groups, such as the Alzheimer's Society, the National Childbirth Trust, or a patient participation group (PPG) at a general practice. Here the number of participants is lower, typically around 8-99, but the involvement is more in-depth, using perhaps a discussion or focus group on the issue or topic being planned or proposed.

Finally, at the pinnacle, level 1, are one or two people, perhaps nominated, invited or selected from the other two levels, who attend the meeting or meetings where the analysis reports of the PPI activity from levels 2 and 3 are discussed. There are the lay representatives who help to ensure that the patient voice is heard where the decision is made. The theory behind this model is that although there are fewer numbers involved at level 1, the influence is greater as this is the point at which formal decisions are made by the organisations. It is also one of the points at which PPI often falters and can undermine the influence of PPI. The involvement of lay representatives in healthcare planning and decision-making, whilst useful as a 'tick-box' exercise, appears to have a more detrimental affect of prejudicing staff against PPI. Lay reps are rarely perceived as representative of patients or patient groups, their involvement is at best tolerated but of no great value or influence. At worst, their involvement is vilified and undermines the ethos of PPI. There are implications here for practitioners who will need to consider carefully the aim of involving individuals in this way. Excluding lay reps at this stage opens debates about power, influence and authority. But what is the added value? What is the influence of lay reps at this level and how and should it be improved?

The findings from the semi-structured interviews show that although staff members purport to believe PPI is important, when asked to say where it fit within their own daily priorities, it did not figure. It could be interpreted that their comments are mere rhetoric, something they felt compelled to say as staff would potentially find it hard to argue that patients or the public should not be involved in decisions that may affect them. However, at the time of the data collection from the interviews, WNPCT was one of the few PCTs in the



country that systematically involved the public in planning and decision-making. Although this activity was predominantly the domain of the Public Involvement Manager, culture change takes time and it was clear the majority of the staff interviewed had an awareness of the concept of PPI that had not just been gleaned from the participant information sheet for the interview.

Practitioners, clinicians and decision-makers want the feedback to feel 'real' to help motivate them into action (Chapters 5, 6 and 7). However, there is also an ethical consideration for participants in PPI which can be described as 'nobody involved in your care will be there'. Robust research methods and representative sampling of the populations affected by any planning or proposals, such as pregnant women for changes to maternity services, or residents using a walk-in service which is earmarked for closure, is crucial. The use of vox pops, brief video recorded clips, of a small sample of those participating in the PPI activity could accompany the report of the PPI outputs to provide this stimulus.

### **9.3 Recommendations for policy and practice**

Public engagement is now commonly seen as the public engaging in public health interventions and social marketing projects, such as smoking cessation and eating five-a-day type activity. What else could it be called that would enable all staff to understand what it is? Does it help that we now have PPI for commissioners of services and 'measuring the patient experience' for providers of services?

Confusion remains regarding the definition of patient and public involvement, patient and public engagement and patient experience. Service providers understand their remit for the latter, as CQUIN builds in quality indicators around measuring the patient experience to improve the quality of services. However, the wider issue of involving the public in the planning and decision-

making process in Trusts, particularly the new provider arms of commissioning PCTs, is less clear. Foundation Trusts place an emphasis on their Governors and Membership, rather than independent research and their influence on services is unclear (Healthcare Commission, 2009).

The findings of the semi-structured interviews regarding the ‘portability’ of PPI through a period of change is in keeping with the report from the House of Commons Select Committee (2006), which asserted that the reconfiguration of PCTs would diminish PPI, citing the reduction in local community based non-executive directors, larger patient and public involvement Forums and that the larger geographic area would make PCTs too remote from their communities. With the publication of the White paper, *‘Liberating the NHS’* (Department of Health, 2010), clusters of GPs are to take on responsibility for commissioning healthcare services for their local population. The literature review has shown that PCTs have struggled to implement effective PPI that influences planning and decision-making, despite world class commissioning competency assurance processes and more emphasis on providing evidence of what action has been done as a result of PPI. Practice based Commissioners (PbC) have struggled to implement effective PPI (Coleman et al., 2009), and new GP commissioners now have the opportunity to learn from the mistakes of the past and ensure (a) that there is expectation and agreement that PPI will influence planning and decision-making from the offset set and (b) measures of success for PPI are based on evidencing what is different as the result of PPI activity.

Furthermore, Local Involvement Networks (LINKs) are to reinvent themselves as HealthWatch. The literature review has described the changing face of the ‘watchdogs’ of the NHS from Community Health Councils, through patient and public involvement forums to LINKs. There is little evidence of the added value such groups have made to planning and decision-making, so here again is an opportunity to note the need for robust project management and agreement on how the success of PPI will be measured.

Over the years I fed into policy via the Strategic Health Authorities and the Department of Health. I actively shared information of work practice backed up with the credibility of the findings.

My practice has improved as a result of this study (see reflexivity in previous chapter). I need to ensure that I do not become complacent and become a barrier again.

In conclusion, I have identified six key enabling steps to ensure patient and public involvement in the NHS influences healthcare planning and decision-making as a result:

1. set and agree measures of success, using the measures to ensure action and continually evaluate and revise to ensure the measures remain appropriate;
2. use a project management process based on action research to ensure follow through;
3. involve patients and carers in the project management, as an action research methodology supports the participatory process;
4. agree the plan of action for patient and public involvement, regardless of whether the PPI is done 'in-house' or is commissioned out to a research company;
5. ensure the output of an independent thematic analysis of the PPI is evaluated and reflected upon as part of the action research project;
6. revise the plans to reflect the changes required, as identified in the PPI analysis report.

## **9.4 Contribution to knowledge**

My contributions to new knowledge are in three key areas: the research subject area, the use of action research to investigate the issue and the usefulness of the findings, as described below:

1. The relative neglect of the specific research problem by previous researchers.
2. Relative neglect of using an action research methodology by previous researchers to investigate this issue. The methodology is justified in Chapter 3.
3. The usefulness of the application of the research findings in influencing national policy and local action– i.e. enabling the needs and views of patients and the public to influence planning and decision-making in the NHS.

Influencing policy makers can be deemed a “significant triumph” when attempting to produce evidence to support claims of new knowledge (McNiff and Whitehead, 2006). Throughout this study, I have shared the new knowledge I have gained with my own organisations, with the NHS East of England Strategic Health Authority and with the Department of Health, resulting in directly influencing the national policy for patient and public involvement (DH Commissioning and System Management - PPE, 2008).

I also present and demonstrate six steps to enable the NHS to implement PPI that influences planning and decision-making in healthcare services as a result (see previous page). These steps have the potential to provide a model for the way patient and public involvement or engagement should be embedded into the commissioning process in the NHS.

## 9.5 Limitations

One of the limitations of this study is a methodological one. It was explained in Chapter 4 that it is difficult to establish criteria for establishing rigour, validity and generalization in an action research study. I therefore ‘hedge my bets’ and use a blend of both traditional and constructivist criteria against which I judge my study. It may have been more appropriate to have adhered to one school of thought, particularly around the use of AR as not only a methodological approach, but also an approach to rigour.

The lack of participation of others from the start of the study, for example fellow practitioners or colleagues within my organisation or patients and the public, could be perceived as a limitation, particularly in the light of Kemmis and McTaggart’s (1997) emancipatory stance to AR. By its very nature, action research is participatory and yet in this study, partly due to my requirements to complete a doctoral thesis and partly due to pragmatism, others are not directly involved until later in the study. Although not unusual, this may have impacted on the process of analysis of the findings and conclusions drawn, which was not done in collaboration with others. Furthermore, the themes from the semi-structured interviews were not tested with the participants for accuracy or validation, as by the time this work was carried out, the organisation no longer existed and staff had either moved to new organisations or left the NHS (see 6.2).

Only one action research cycle was implemented due to the publication of the White Paper which required a rapid reconfiguration of PCTs (Department of Health, 2005a). This is a limiting factor, as further sharing and exploration of the initial actions may have provided further insight into the issues both of embedding PPI into a project management process.

There were limitations in terms of time, due to the reconfiguration looming and the change of the organisation, the opportunity was lost for a more in-depth investigation of the issues using the action research cycle. A more protracted study would have allowed the cycle to have been followed through to at least the beginning of the second cycle, if not beyond, and may have highlighted other issues impacting on the area of interest.

It has been argued that analysis of interpretation of data should be done by the researcher during the enquiry, rather than waiting until the end (Pope *et al.*, 1999). Others point out that there is a vast amount to be done after the field work (Pope *et al.*, 1999). In this instance, due to the change of my role to lead the forthcoming reconfiguration of PCTs, analysis was implemented after the enquiry. Indeed, this very distance from the initial data collection provided a new reflection on the findings (see reflexive chapter).

This study focussed on one organisation, which may in itself have been a limitation. A design that enabled the use of two or more PCTs may have been more valuable, though it is noted that PCTs across the country were going through a period of merger and reconfiguration, which may have made it very difficult to have encompassed more than one organisation.

In both the rigour and the ethics section of this thesis, and further in my chapter on reflexivity, I discuss my presence in terms of impact on the participants and therefore this must be considered as a potential limitation. My close working with senior management, my pivotal role in the subject matter of public involvement, and being a colleague working in the same organisation may all have influenced the willingness, or not, of staff to participate and their responses. Although I considered myself to be an insider researcher, as I was studying PPI, for which I was responsible, the participants of the AR meetings may not have considered me to be an insider to their team. Although I was working with them on the AR project, they were all healthcare staff from a

specific directorate and I was part of the corporate management of the organisation.

## **9.6 Further research**

- Given the speed of organisational change, a key question is how can one produce research that will hold its value over time, i.e. research that does not apply to a single organisational structure?
- There is a need for further exploratory research on how measures of success for PPI can be identified.
- Future research should address the application of the new model for implementing PPI that influences planning and decision-making. Such a study should closely monitor the process and outcome of introducing such changes in practice.
- This study highlights the limitations of carrying out an action research study during a period of significant organisational change. The intended action research cycles were not followed due to the impending reconfiguration and potential job changes and losses. Further study could be undertaken to explore the effectiveness of the use of AR as a methodology during periods of organisational change.
- Research is needed to assess the impact of recent policy changes on GPs. With the forthcoming remit on GPs to commission healthcare services in the near future, the legislative requirement for PPI will also shift. Research into the attitudes of GP towards involvement of patients and the public in the commissioning planning and decision-making

process at a wider level than patient participation groups would be prudent.

## **9.7 Conclusion**

Patient and public involvement in the NHS continues to be promoted by consecutive Governments in England and yet it is clear that the influence of such PPI activity on planning and decision-making remains patchy or nominal. This study has focussed on one organisation, using an action research methodology, to consider how the NHS can demolish the ‘brick wall’ between the outputs of PPI activity and the outcome in terms of healthcare decision-making identified by researchers, regulatory and monitoring organisations.

Using an action research methodology, a document review, semi-structured interviews and AR team meetings were implemented. The findings show that WNPCT, despite being advertised and rewarded as an organisation at the forefront of PPI, had the same brick wall identified in other healthcare organisations.

Two key findings are firstly the measures of success used both internally and externally for PPI, which focus on PPI activity rather than the outcome and secondly, the lack of follow through that enables PPI to influence planning and decision-making. In this final chapter I make recommendations for policy and practice based on my findings, identify limitations in my study and make recommendations for further research.

During the period of this study, the healthcare landscape changed with PCTs reconfigured into larger, merged organisations, latterly divesting themselves of their healthcare provision responsibilities to focus on world class commissioning. Participants in the study spoke of their fear of the future, both for themselves and for the ethos of patient and public involvement in NHS



planning and decision-making. In addition, I had to apply for a job in the new PCT that would enable me to continue both my work and my research of PPI. This study concludes on the cusp of yet further major change with the publication of *'Liberating the NHS'* (Department of Health, 2010), which will see the abolition of PCTs and the responsibility of healthcare commissioning passing to clusters of GP commissioners.

As I write these final paragraphs, I am once again preparing myself to vie with others for a job in the new world of GP commissioning and I am debating the threats and opportunities to ensure that PPI continues to be a driver for change and continue to improve my practice in the light of my study.

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## APPENDIX 1: ACTION RESEARCH TYPOGRAPHY

Action research typology (adapted from Hart and Bond)<sup>3</sup>

Action research type: distinguishing criteria	<i>Consensus model of society</i> <i>Rational social management</i>	←—————→		<i>Conflict model of society</i> <i>Structural change</i>
	Experimental	Organisational	Professionalising	Empowering
1 Educative base	Re-education Enhancing social science or administrative control and social change towards consensus	Re-education or training Enhancing managerial control and organisational change towards consensus	Reflective practice Enhancing professional control and individuals' ability to control work situation	Consciousness raising Enhancing user control and shifting balance of power; structural change towards pluralism
	Inferring relationship between behaviour and output; identifying causal factors in group dynamics Social scientific bias, researcher focused	Overcoming resistance to change or restructuring balance of power between managers and workers Managerial bias or client focused	Empowering professional groups; advocacy on behalf of patients or clients Practitioner focused	Empowering oppressed groups User or practitioner focused
2 Individuals in groups	Closed group, controlled, selection made by researcher for purposes of measurement, inferring relationship between cause and effect Fixed membership	Work groups or mixed groups of managers and workers, or both Selected membership	Professional(s) or (interdisciplinary) professional group, or negotiated team boundaries Shifting membership	Fluid groupings, self selecting or natural boundary or open/closed by negotiation Fluid membership
3 Problem focus	Problem emerges from the interaction of social science theory and social problems Problems relevant for social science or management interests Success defined in terms of social sciences	Problem defined by most powerful group; some negotiation with users Problem relevant for management/social science interests Success defined by sponsors	Problem defined by professional in group; some negotiation with users Problem emerges from professional practice or experience Contested, professionally determined definitions of success	Emerging and negotiated definition of problem by less powerful group(s) Problem emerges from members' practice or experience Competing definitions of success accepted and expected
4 Change of intervention	Social science experimental intervention to test theory or generate theory, or both Problem to be solved in terms of management aims	Top down, directed change towards predetermined aims Problem to be solved in terms of management aims	Professionally led, predefined, process led Problem to be resolved in the interests of resolved in the interests of research based practice and professionalisation	Bottom up, undetermined, process led Problem to be explored as part of the process of change, developing an understanding of meaning of issues in terms of problem and solution
5 Improvement	Toward controlled outcome and consensual definition of improvement	Towards tangible outcome and consensus definition of improvement	Towards improvement in practice defined by professionals and on behalf of users	Towards negotiated outcomes and pluralist definitions of improvement: account taken of vested interest
6 Cyclic processes	Research components dominant Identifies causal processes that can be generalised Time limited, task focused	Action and research components in tension; action dominated Identifies causal processes that are specific to problem context or can be generalised, or both Discrete cycle, rationalist, sequential	Research and action components in tension; research dominated Identifies causal processes that are specific to problem or can be generalised, or both Spiral of cycles, opportunistic, dynamic	Action components dominant Changes course of events; recognition of multiple influences upon change Open ended, process driven
7 Research relationship, degree of collaboration	Experimenter or respondents Outside researcher as expert or research funding Differentiated roles	Consultant or researcher, respondent or participants Client pays an outside consultant—"they who pay the piper call the tune" Differential roles	Practitioner, or researcher or collaborators Outside resources or internally generated, or both Merged roles	Practitioner researcher or coresearchers or co-change agents Outside resources or internally generated, or both Shared roles

(Hart and Bond, 1998)

**APPENDIX 2 – TABLE OF PPI ACTIVITY AND REPORTED CHANGE  
AS A RESULT**

<b>Project</b>	<b>PPI method</b>	<b>Year</b>	<b>Reported change as a result</b>
1.	Conference with workshops	2000	Further conference to take forward actions of the first conference
2.	Three public methods	2000	No report found
3.	Questionnaires and focus groups	2000	None reported
4.	Focus groups	2000	None reported
5.	Questionnaire	2000	Study day for receptionists covering attitude towards client group
6.	Conference with workshops	2001	None reported
7.	Conference with workshops	2001	Commitment from Chair of Board to take actions forward
8.	Conference with workshops	2001	Model of care adapted to reflect views Commitment to another conference in a year
9.	3-day Conference with workshops	2002	None reported
10.	Conference with workshops followed by young people's reference group meetings	2002	Feedback on outcomes said that work would be done, but none reported
11.	Conference with workshops	2002	Commitment to carry on taking action and a conference in another year
12.	Conference with workshops	2003	Commitment to carry on taking action and a conference in another year
13.	Questionnaire	2003	Options for improved environment investigated and some, but not all, implemented
14.	Questionnaire	2003	No report found
15.	Two day conference	2003	Patients are more confident and working on anti-bullying Carers looking at ways or sharing their experience with younger carers Private providers supporting each other with training costs Carers looking at violence and fear in the home Looking at wider use of everyday services for work, leisure and health
16.	Focus groups	2003	None
17.	Three public meetings and questionnaire	2003	None reported
18.	Discovery interviews	2004	Healthcare professionals to receive training in specific areas More health professionals to be recruited
19.	Conference with workshops	2004	Implementation group to decide how to put ideas into action
20.	Questionnaire	2004	None
21.	Postal survey	2004	Patient information notices to be displayed explaining waiting times

			Potential to improve confidentiality through environment
22.	Reference group meeting and questionnaire	2004	No report found
23.	Focus groups and questionnaires	2004	Influenced strategy for WNPCT Training programme Risk assessment tool produced Falls service to take referrals for equipment
24.	Focus groups	2004	None reported
25.	Not stated	2004	None reported
26.	Focus groups	2004	Devised a leaflet based on feedback from patients and carers and promised to audit in 6 months
27.	User group	2004	Library contacted to come to hospital
28.	Survey and interviews	2004	Two eight-session evening programmes offered
29.	Conference with workshops, open day, public meeting	2005	Hospital remained closed as NHS facility, but enabled to open as a registered charity with NHS services
30.	Questionnaires	2005	Respondents were invited to take part in a patient reference group
31.	Questionnaire	2005	Revisions to purple book made as result
32.	Focus group	2005	None reported
33.	Postal survey	2005	None reported
34.	Focus groups	2005	Feedback used to put in bid for funding
35.	Postal survey	2005	Informed equality and diversity work
36.	User group meetings	2005	Wet-room installed in 2 venues Quiet rooms provided Multi-racial/faith welcome sign put at all reception points
37.	Postal survey	2005	Team looking to see how they can use the results to plan Choose and Book in WNPCT
38.	Postal survey	2005	Local leaflet developed with information as requested
39.	Postal survey	2005	New group set up and running and opportunity to see patient before groups sessions
40.	Postal survey	2005	Information used by pharmacy contract implementation group to decide what enhanced services to provide
41.	Survey	2005	None reported
42.	Focus groups	2005	None reported
43.	Discovery interviews	2005	None reported
44.	Discovery interviews	2005	None – due to lack of participants
45.	Focus group	2006	None reported
46.	Leaflet inviting comments	2006	None reported

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## APPENDIX 3: SEMI-STRUCTURED INTERVIEWS PARTICIPANT INFORMATION SHEET

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### RESEARCH PARTICIPANT INFORMATION SHEET

#### **Patient and Public Involvement in the NHS – enabling the implementation of Section 11 of the Health and Social Care Act 2001**

#### **Invitation**

You are being invited to take part in a research study. Before you decide 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 discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. *Thank you for reading this.*

#### **What is the purpose of the study?**

My name is Trish Turner and I am the Public Involvement Manager for West Norfolk Primary Care Trust. I am also a PhD student with the University of East Anglia, researching the impact of the Patient and Public Involvement arrangements within West Norfolk Primary Care Trust as described in Section 11 of the Health and Social Care Act of 2001. The research aims to:

- Study to what extent the policy has been put into practice
- Explore staff understanding, values and beliefs towards involving the public
- Investigate if staff believe changes to patient care have been made as a result and
- Recommend what more needs to be done

The Modernisation Agency and Norfolk, Suffolk and Cambridgeshire Strategic Health Authority say this is an important study as it fills an important gap in our learning about the implementation of the patient and public involvement policies.

The data collection part of the study will take two years to complete and will be used towards the attainment of my Ph.D (doctorate) which is due to be completed by 2008 – 10.

#### **Why have I been asked to take part?**

You have been asked to take part in this study because you work for West Norfolk Primary Care Trust. A maximum of 50 people in total will be asked to take part.

#### **Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your job or career.

#### **If I agree to take part, what happens next?**

If you agree to take part in the study, you will need to sign the CONSENT FORM I have sent you with this letter. This says that you agree to take part in the study and understand what will happen to you. Once you have given your consent, I, or my secretary Diana Thurley, will contact you and arrange a time for an interview. This can take place in a suitable neutral venue.



All interviews will be recorded either with a tape or digitally. All recordings will be kept in a locked cabinet at my home and I will be the only person to have access to them. Once the research has been completed (by 2010) the recordings will be erased. Your name will be removed from all written documents, which result from the interviews.

### **What do I have to do?**

If you agree to take part I will ask you to answer some questions. There aren't any right or wrong answers – I just want to hear your opinions. The discussion should take about an hour and a half at the longest.

### **What are the possible benefits of taking part?**

We expect to generate feedback for further development of patient and public involvement within West Norfolk Primary Care Trust and the wider NHS. By participating in the study you will have a chance to have your input into further development of your organisation's lay involvement initiatives.

You will not get any personal benefit from taking part in this study. There are no costs associated with taking part in this study. You will not receive compensation for participating in this study.

### **What if something goes wrong?**

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you.

### **Will my taking part in this study be kept confidential?**

All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you will have your name removed so that you cannot be recognised from it. No identifiable information will be given to your direct managers and/or the Human Resources Department

### **What will happen to the results of the research study?**

The results of the interviews will be analysed then one team or department will be invited to participate further as part of an action research project. All of these results will be published on an ongoing basis as they become available, from approximately 3 months after the start of the interview process. You can obtain a copy of the published results from me or directly from the PCT Intranet. You will not be identified in any report/publication.

### **Who is organising and funding the research?**

The research is being organised by the Public Involvement Manager as part of her doctoral study supervised by the University of East Anglia. West Norfolk Primary Care Trust is funding the research.

### **Who has reviewed the study?**

The Local Research Ethics Committee reviewed and approved this study.

### **Contact for Further Information**

If you have any further questions you would like to ask about the project then please contact me, Trish Turner, Public Involvement Manager, West Norfolk Primary Care Trust on 01553 816217, my mobile 0777 177 2155, or at the address at the top of this sheet and I will be happy to answer any questions you may have.

Thank you for taking part in this study.

*You will be given a copy of this information sheet and a signed consent form to keep.*

**APPENDIX 4: CONSENT FORM – SEMI-STRUCTURED INTERVIEWS**

**CONSENT FORM**

**Title of Project:**

Patient and Public Involvement in the NHS – enabling the implementation of Section 11 of the Health and Social Care Act 2001

**Name of Researcher:** Trish Turner

**Please Initial Box**

1	I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.	
2	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.	
3	I agree to the meetings being audio-taped/digitally recorded.	
4	I also understand that I have the right to ask for the audiotape/recording to be turned off at any time during meetings.	
5	I agree to participate in this study under the conditions set out in the Information Sheet.	
6	I would like to have a summary copy of the results of this study.	

\_\_\_\_\_ Date \_\_\_\_\_ Signature \_\_\_\_\_ Print Name

Address and contact details:

\_\_\_\_\_ Researcher \_\_\_\_\_ Date \_\_\_\_\_ Signature

Please return this consent form to Trish Turner at the address below:

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**APPENDIX 5: SEMI-STRUCTURED INTERVIEW QUESTIONS**

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**SEMI-STRUCTURED INTERVIEW QUESTIONS**

<b>Role</b>	Please could you tell me a little about your role within the PCT?
	How long have you been in the NHS? How did you get to this point of your career?
	How much contact with patients or the public do you have in your current role?
	For how many members of staff are you responsible?
<b>Understanding</b>	In your view, what do you think constitutes PPI in primary care? (What does PPI mean?)
	What is your understanding of the NHS Patient and Public Involvement Policy and legislation?
	What do you understand to be the PCT's vision for PPI?
	What training, if any, have you received around PPI? How were you able to put this into practice? Did it help? If none, would you have liked to receive any? If so, what?
<b>Experience</b>	What have been your experiences of PPI within WNPCT?
	Please can you give an example of where you may have carried out public involvement activity in your department?
	How have services changed as a result of this? Please describe.
	Please can you give me an example of where in your practice, patient views and experiences have had an impact on the way you work?
<b>Values and Beliefs</b>	How important do you think it is to involve patients and the public in the decision-making process around the services the PCT provides? Why?
	How possible do you think it is to achieve? Why?
	What do you think are the barriers to PPI? How do you think the barriers could be overcome?
	Where does PPI fit into your work priorities? Why?
	What do you think is the PCT's level of commitment to PPI? Why?
<b>Changes</b>	Do you think PPI is working in the local NHS? Why?
	If PPI could be further developed, what do you think could be done?
<b>Portability</b>	The NHS is about to go through a major reconfiguration. What do you think are the implications for PPI? Nationally? Locally? For you?

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## APPENDIX 6: ACTION RESEARCH TEAM PARTICIPANT INFORMATION SHEET

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### ACTION RESEARCH PARTICIPANT INFORMATION SHEET

#### Patient and Public Involvement in the NHS – enabling the implementation of Section 11 of the Health and Social Care Act 2001

##### Invitation

You are being invited to take part in a research study. Before you decide 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 discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. *Thank you for reading this.*

##### What is the purpose of the study?

My name is Trish Turner and I am the Public Involvement Manager for West Norfolk Primary Care Trust. I am also a PhD student with the University of East Anglia, researching the impact of the Patient and Public Involvement arrangements within West Norfolk Primary Care Trust as described in Section 11 of the Health and Social Care Act of 2001. The research aims to:

1. *Investigate to what extent the PPI policy has been put into practice;*
2. *Explore staff values and beliefs regarding involving the public;*
3. *Investigate if staff believe changes or improvement to patient care have been made as a result of PPI activity;*
4. *Given the analysis of the above, to consider and identify what the attributes and enabling factors are that facilitate PPI that leads to change.*

The Modernisation Agency and Norfolk, Suffolk and Cambridgeshire Strategic Health Authority say this is an important study as it fills an important gap in our learning about the implementation of the patient and public involvement policies.

The data collection part of the study will take two years to complete and will be used towards the attainment of my Ph.D (doctorate) which is due to be completed by 2008 -10.

##### Why have I been asked to take part?

You have been asked to take part in this study because you work for West Norfolk Primary Care Trust.

##### Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your job or career.

##### If I agree to take part, what happens next?

If you agree to take part in the study, you will need to sign the CONSENT FORM I have sent you with this letter. This says that you agree to take part in the study and understand what will happen to you. Once you have given your consent, you will be invited to attend the first of several meetings with some of your colleagues, plus me, as facilitator.

The meetings may be recorded either with a tape or digitally. All recordings will be kept in a locked cabinet at my home and I will be the only person to have access to them. Once the research has been completed (by 2010) the recordings will be erased. Your name will be removed from all written documents, which result from the interviews.

### **What do I have to do?**

If you agree to take part, you will be asked to participate in something called 'Action Research', as a member of the Action Research Team. You will be asked to come to an initial meeting of the AR Team to find out more of what is involved. At that meeting there will be an informal talk about public involvement within your team. Members will then agree how often they want to meet, how the meetings will be recorded and will plan together any action. The meetings usually take up to two hours every two weeks, for a total of six months, but this is negotiable with team members.

### **What are the possible benefits of taking part?**

We expect to generate feedback for further development of patient and public involvement within West Norfolk Primary Care Trust and the wider NHS. By participating in the study you will have a chance to have your input into further development of your organisation's lay involvement initiatives.

You will not get any personal benefit from taking part in this study. There are no costs associated with taking part in this study. You will not receive compensation for participating in this study.

### **What if something goes wrong?**

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you.

### **Will my taking part in this study be kept confidential?**

The Action Research Team discussions will be recorded and written up. However, all ideas or opinions expressed in discussion will be kept confidential from anyone outside of each discussion group. Within group work, any breach of the predetermined ground rules will be dealt with within the group. Participants will not be individually identified in written reports or articles. All recordings made will be destroyed once the project is completed.

### **What will happen to the results of the research study?**

All of the results will be published on an ongoing basis as they become available. You can obtain a copy of the published results from me or directly from the PCT Intranet. You will not be identified in any report/publication.

### **Who is organising and funding the research?**

The research is being organised by the Public Involvement Manager at West Norfolk Primary Care Trust as part of her doctoral study supervised by the University of East Anglia. West Norfolk Primary Care Trust is funding the research.

### **Who has reviewed the study?**

The Local Research Ethics Committee reviewed and approved this study.

### **Contact for Further Information**

If you have any further questions you would like to ask about the project then please contact me, Trish Turner, Public Involvement Manager, West Norfolk Primary Care Trust on 01553 816217, my mobile 0777 177 2155, or at the address at the bottom of this sheet and I will be happy to answer any questions you may have.

**Thank you for taking part in this study. You will be given a copy of this information sheet and a signed consent form to keep.**

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**APPENDIX 7: CONSENT FORM - ACTION RESEARCH TEAM**

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**CONSENT FORM****Title of Project:**

Patient and Public Involvement in the NHS – enabling the implementation of Section 11 of the Health and Social Care Act 2001

**Name of Researcher:** Trish Turner

**Please Initial Box**

1	I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.	
2	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.	
3	I agree to the meetings being audio-taped/digitally recorded.	
4	I also understand that I have the right to ask for the audiotape/recording to be turned off at any time during meetings.	
5	I agree to participate in this study under the conditions set out in the Information Sheet.	
6	I would like to have a summary copy of the results of this study.	

\_\_\_\_\_

Date

\_\_\_\_\_

Signature

\_\_\_\_\_

Print Name

Address and contact details:

\_\_\_\_\_

Researcher

\_\_\_\_\_

Date

\_\_\_\_\_

Signature

Please return this consent form to Trish Turner at the address below:

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## APPENDIX 8: ETHICS APPROVAL

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### East Norfolk & Waveney Research Governance Committee



Please reply to: Research & Development Office  
Medical Education Centre, Room 032  
Level 3, East Block  
Norfolk & Norwich University Hospital  
NHS Trust  
Colney  
Norwich  
NORFOLK

Telephone: 01603 287408  
Fax: 01603 289800  
E-mail: frances.barton@nnuh.nhs.uk

14 JUN 2004

Ref: 86-06-04

Mrs P Turner,  
West Norfolk Primary Care Trust  
St James  
Extons Road  
Kings Lynn  
Norfolk  
PE30 5NU

08 June 2004

Dear Mrs Turner,

**ID: 2004CM23**

**Patient and Public Involvement in the National Health Service (NHS) -  
Enabling the Implementation of Section 11 of the Health and Social  
Care Act, 2001. Student project PhD**

Thank you for submitting the above project, which was discussed at the Research Governance Committee meeting last week. Members agreed that this study was of a high quality, well written and thoughtfully prepared. However, there was one point which the Committee would like changed; the information sheet for participants should mention that they would be re-interviewed. Please send a revised version of the information sheet to the R&D office.

On behalf of the Committee, I am pleased to inform you that your project has been given full approval. The standard terms and conditions of approval are enclosed, please sign and return one copy to the R&D office. Failure to return a signed copy of the standard terms and conditions of approval may affect the conditions of approval.

Please keep this Committee fully informed of any proposed changes in this study.

For your information I am enclosing a copy of the Members List for the Committee.

If you have any queries regarding this study please contact Frances Barton, Research Governance Committee Administrator, at the above address.

I would like to take this opportunity to remind you that although you have full approval from the Research Governance Committee, you should not commence your study until you have full approval from the Local Research Ethics Committee.

Please see overleaf.



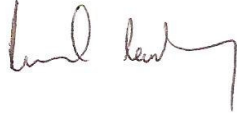
**IMPORTANT – PLEASE NOTE**

Procedures for the LREC have recently been revised.

Following the new operating procedures for Research Ethics Committees (RECs) that have come into force nationally from 1st March 2004 it is now necessary for local Investigators to book in their application with their Local Research Ethics Committee office. This will enable your application to be allocated a slot on the next available Ethics Committee agenda, or if the local agenda is full, be allocated to another Research Ethics Committee within the Strategic Health Authority Area.

Therefore I would strongly advise that you contact the Ethics office to discuss your submission. The Norwich Local Research Ethics office contact details are: telephone 01603 289813 or e-mail [janette.guymer@nnuh.nhs.uk](mailto:janette.guymer@nnuh.nhs.uk) . I can confirm that multiple copies of your submission have been sent to the Norwich Local Research Ethics Committee.

Yours sincerely



Dr Richard Reading

**Vice Chair  
Consultant Paediatrician - Norwich PCT**

Encs

12 JUL 2004



**King's Lynn Local Research Ethics Committee**

c/o Library/Knowledge Services  
The Queen Elizabeth Hospital  
Gayton Road  
King's Lynn  
Norfolk  
PE30 4ET.

Tel. 01553 613269  
Fax. 01553 613883

Mrs Patricia Turner  
Public Involvement Manager  
West Norfolk Primary Care Trust  
St James  
Extons Road  
King's Lynn  
PE30 3NU.

09 July 2004

Dear Mrs. Turner

***Patient and Public Involvement (PPI) in the National Health Service (NHS) -  
Enabling the Implementation of Section 11 of the Health and Social Care Act  
2001***  
**REC reference number: 04/Q0105/11**

The Research Ethics Committee reviewed the above application at the meeting held on 08 July 2004.

The members of the Committee present gave a favourable ethical opinion to the above research on the basis described in the application form, protocol and supporting documentation.

**The favourable opinion applies to the following research site:**

West Norfolk Primary Care Trust

**Conditions of approval**

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

The documents reviewed and approved at the meeting were:

**Application**

Version: 3.0

Dated: 13/05/2004

Date Received: 15/06/2004

**Investigator CV**

Dated: 15/06/2004

Date Received: 15/06/2004

**Protocol**

Dated: 15/06/2004

Date Received: 15/06/2004

**Covering Letter**

Dated: 14/06/2004

Date Received: 15/06/2004

**Peer Review**

Dated: 08/06/2004

Date Received: 15/06/2004

**Participant Information Sheet**

Version: 1

Dated: 01/05/2004

Date Received: 15/06/2004

**Participant Consent Form**

Version: 1

Dated: 01/05/2004

Date Received: 15/06/2004

**Curriculum Vitae for Professor Brian Salter**

**Educational Supervisor**

Dated: 15/06/2004

Date Received: 15/06/2004

**Management approval**

The study may not commence until final management approval has been confirmed by the organisation hosting the research.

All researchers and research collaborators who will be participating in the research must obtain management approval from the relevant host organisation before commencing any research procedures. Where a substantive contract is not held with the host organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

We shall notify the research sponsor, West Norfolk PCT, that the study has a favourable ethical opinion.

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

Yours sincerely,

A handwritten signature in black ink, appearing to read "Ann Osborne". The signature is written in a cursive, flowing style.

**Ann Osborne**  
**Committee Administrator**

