BECOMING PART OF BEHIND THE SCENES: PATIENTS' EXPERIENCES OF CO-LEARNING WITH PRIMARY HEALTH CARE TEAMS

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Louise Worswick

**Becoming part of behind the scenes:
patients' experiences of co-learning with primary health care teams**

Abstract

Current debates about the involvement of health service users in service delivery, research and education focus on the purpose of their involvement, the methods of their involvement, barriers to their involvement and the impact of their involvement. There is little reported about the experience of service user involvement from the service user perspective although some reports are beginning to emerge.

This research study explored the experiences of a group of health service users (patient representatives) who brought their experience of being a patient to contribute to an educational initiative about quality improvement and back pain. That study – the Learning to Improve the Management of Back Pain in the Community (LIMBIC) project, utilised a mixed methods approach to evaluate the impact of the educational initiative on clinical practice and patient outcomes for the management of back pain.

Eleven patient representatives, uniquely placed as co-learners, participated with general practice teams learning about quality improvement principles and methods and implementing quality improvements in practice. To build on this learning initiative, the current study used semi-structured interviews to explore the patient representative experience and integrated the findings with existing LIMBIC data.

The study illuminated aspects of the service user experience which led to the proposal for a model for co-learning with service users to bring about change. It contributes to the wider knowledge of service user involvement by identifying features of their experience that worked well for them and features that could be improved. The co-learner role is a new direction for service user involvement and represents a new movement in the field of inquiry about opportunities for service user involvement in the future. A debate has been opened about managing expectations of service users and about their potential for leadership and influencing change.

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This study describes a journey which has been shared in part with a group of research participants whose stories made the research possible. Their contribution formed the core of this study and for their time and commitment I am deeply grateful.

A previous study, the Learning to Improve the Management of Back Pain in the Community (LIMBIC) project which was undertaken at Bournemouth University with the support of an award from the Health Foundation led to the idea for this research. I am grateful to Bournemouth University and the Health Foundation for making this current study possible and to the co-principal investigators of the LIMBIC project, Professor Eloise Carr and Dr Charles Campion-Smith.

As a postgraduate researcher undertaking this doctoral thesis I have been supported by a supervisory team of experts namely, Dr Christine Little, Dr Kath Ryan, Professor Kathleen Galvin and Professor Eloise Carr and I am hugely grateful to all of them.

Author's Declaration

Elements of this thesis have been previously presented at conferences and papers have been submitted for publication. The details of these are given in Appendix 1.

This thesis is an independent work and the primary data collection and analysis is original research but does draw upon a prior study which is referred to throughout the thesis – the Learning to Improve the Management of Back Pain in the Community (LIMBIC) project. Appendix 1 also gives the details of the role of the author in relation to the LIMBIC project.

This research is the sole work of the author and where data from the prior study is used and re-analysed, this is indicated throughout the text.

1.   Background to the study

This study was undertaken in a University in the South of England between March 2008 and December 2012. It involved participants from National Health Service general practice settings including staff and patients. The story starts in 2008 soon after I had left my clinical governance position in a healthcare commissioning organisation to commence a new researcher role in an academic institution. I had been appointed project manager and researcher for a three year externally funded mixed methods research project which was an evaluation of an interprofessional education initiative. The principles of quality improvement and the application of quality improvement tools provided the focus for learning in relation to the management of back pain. Each general practice team included a representative from their patient client base who, as service user, provided a patient perspective on back pan. Through my involvement in that study, the idea for this current research emerged.

1.1   Quality improvement in health services

With the availability of funding to support healthcare a constant challenge, healthcare organisations have been required to develop new ways of working to meet the needs of patients in cost effective and clinically effective ways. The implementation of clinical governance across the United Kingdom (UK) National Health Service (NHS) and the monitoring of this through quality improvement reviews by the regulator, the Care Quality Commission (formerly the Healthcare Commission and the Commission for Health Improvement), went some way towards improving health care practice. Earlier terms used to describe quality improvement included 'continuous quality improvement' and 'total quality management' and represent a set of values and tools which are used for setting goals, planning, implementing and measuring change (Dawda et al. 2010). These quality improvement tools originated from the United States with Deming's (1982) transformation of management styles in the manufacturing and service industries and in the motor industry in Japan (Juran 1988). Don Berwick (2001) leading the Institute for Healthcare Improvement in the United States transferred these ideas

into health care with a particular focus on patient safety as a goal of quality improvement. Batalden and Davidoff (2007, p2) defined quality improvement as:

> "…the combined and unceasing efforts of everyone - healthcare professionals, patients and their families, researchers, payers, planners and educators - to make the changes that will lead to better patient outcomes (health), better system performance (care) and better professional development…"

Quality improvement is still a high priority for healthcare institutions as its impact on cost efficiency and clinical outcomes is well recognised (Øvretveit 2009).

Guidance that emerged from the Department of Health (2003) in England and the United States (Berwick and Leape 1999; Kohn et al. 1999) placed quality improvement at the heart of health care planning and delivery because it focused on the aspects of care which were important to patients and it had the potential for cost savings.

1.2   Involving service users in quality improvement

The emergence of clinical governance in the 1990s in the UK offered a strategic framework that would ensure that adequate systems and processes were in place to support high quality care. Pillars of clinical governance included clinical audit, risk management, clinical effectiveness and patient and public involvement (Scally and Donaldson 1998). Healthcare organisations developed strategies which embraced the concept of patient and public involvement and health care staff were encouraged to involve patients in planning, delivering and evaluating health care (Department of Health 2002a; Pickard et al. 2002; Department of Health 1999). In support of the involvement of patients and the public across the health sector, Glynn et al. (2008, p7) argued that "change will only happen if services are shaped by the people who rely on them." Also known as service user involvement, patient and public involvement in quality improvement is still evident today as the quality improvement agenda has remained a priority. In striving for improvements in the quality of patient care, there have been calls for practitioners to measure the quality of their clinical care alongside the quality of patient experience in order to identify deeper rooted problems such as poor access and communication (Raleigh and Frosini 2012).

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Various definitions have been used to describe service user involvement (Staley 2009; Esson et al. 2009; Andersson et al. 2008; INVOLVE 2004; Chambers et al. 2004; Oliver et al. 2000). INVOLVE (See Glossary) distinguishes between active involvement in research as research participants compared to being actively involved in the research process itself (INVOLVE 2009a). For clarity, and in recognition of the range of alternative terminology, definitions for this and other terms used in this thesis are provided in the Glossary.

Reflecting the changes in the prominence and value placed upon service user involvement today, a current definition of service user involvement in health demands acknowledgement:

> "Involvement means having the patient voice heard at every level of the service, even when that voice is a whisper."

> (Berwick in National Advisory Group on the Safety of Patients in England 2013, p18)

Measuring the impact of service user involvement has become a continuing challenge and it has been shown that this is due in part to the fact that the aims of involving service users are not always made clear (General Social Care Council 2012). This applies to service user involvement in quality improvement, in education and in research, as well as patient involvement in health care. The body of literature debating the impact of service user involvement evolved throughout the many years of promoting service user involvement and increased opportunities for user involvement have also been demonstrated (Staley 2009). A recent study however showed that only 19 per cent of researchers who applied to the UK National Research Ethics Service for approval for their research were intending to involve the public in their research (Tarpey 2011). There have also been suggestions that researchers are paying lip service to national imperatives, taking a tokenistic approach to patient involvement or ticking the box (Craig 2008; Coulter and Ellins 2007; Nilsen et al. 2006; Dewar 2005; Meyer 2000) therefore making this an aspect of practice that is worthy of further study.

1.3   The management of back pain

Increasing pressure on health service spending, alongside new evidence of best practice to support the effectiveness of self-care, led over a decade ago to the prioritisation of proactive self-management for people with long term conditions (Department of Health 2005; World Health Organisation 2002; Barlow et al. 2002). Long term conditions account for up to 70 per cent of the health budget in the UK and many of these are of musculoskeletal origin (Department of Health 2011). Chronic back pain is one of these conditions, managed by clinicians in primary care and supported by evidence-based guidance from the National Institute for Health and Care Excellence, formerly the National Institute for Health and Clinical Excellence (NICE 2009) and the Royal College of General Practitioners (RCGP 2001). For people who have suffered back pain, the impact on their lives covers a range of bio-psycho-social factors, which have been studied through many years of research but despite much evidence-based guidance, chronic back pain is still a continuing health problem and is poorly managed in primary care (Maniadakis and Gray 2000). Numerous reasons have been cited for this, including lack of confidence on the part of GPs who are required to assess and provide advice on management of the condition (Breen at al. 2007). Educational support for GPs and other primary care professionals goes some way towards supporting them in this challenging task. There is scope for the involvement of service users in educational activities and this has been shown to be favoured by GPs who struggle with managing back pain (Breen at al 2007). The involvement of service users in developing and delivering educational activities can stimulate health care professionals to undertake their clinical practice in a way that involves patients as active partners with them in designing and managing their care (Spencer et al. 2011; Dawda et al. 2010; Cooper and Spencer-Dawe 2006; Hasman et al. 2006).

1.4   Context of the study

The Learning to Improve the Management of Back Pain in the Community (LIMBIC) project evaluated an educational initiative that involved service users. In the context of the LIMBIC project the service users were referred to as patient representatives. In a primary care setting for the learning environment, the LIMBIC project involved a series of eight workshops with nine general practice teams. The teams attending the

workshops comprised a mix of clinical and non-clinical practice staff and each team included a patient representative. The project evaluated the impact of the practice teams' learning about quality improvement and their management of patients with back pain. The patient representatives participated in the workshops learning about continuous quality improvement principles and methods and working with practice teams in identifying and implementing changes in their GP practice (Carr et al. 2012; Breen at al. 2011).

As well as being about service user involvement in research the LIMBIC project was also about the involvement of service users in developing health services in relation to the management of back pain. The LIMBIC project itself was about improving health services, it was about interprofessional education and it was designed as a mixed method research study. There were levels of evaluation at different times during the educational delivery and practice teams and patients were involved at different times in being part of those evaluation processes. Appendix 2 illustrates the levels of evaluation of the LIMBIC project and where patient representatives were involved in these processes.

The components of the LIMBIC project were education, research, service delivery, the management of back pain, service user involvement, interprofessional education and the teaching of the principles and methods of quality improvement (Figure 1).

Principles and methods of quality improvement	Management of back pain	Using evidence to influence improvement
Improvement learning	Interprofessional education	User involvement
Health	Education	Research
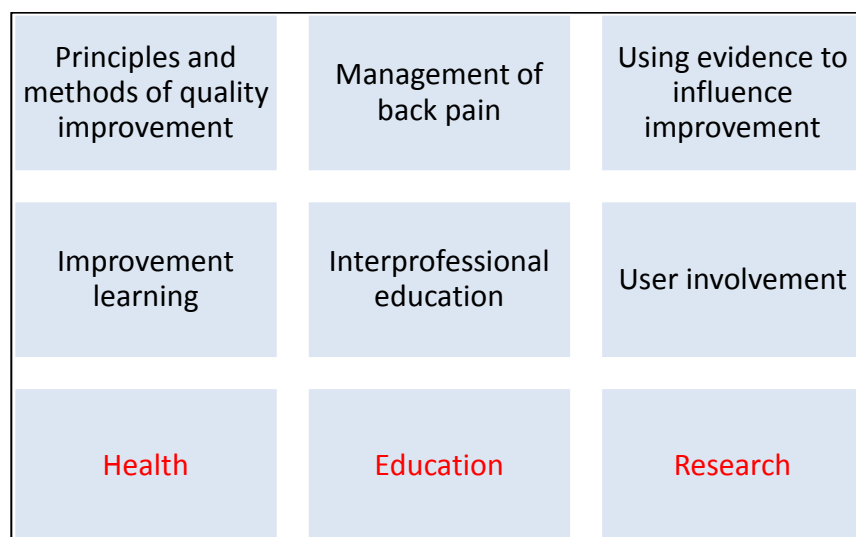
Figure 1. Components of the LIMBIC project

At the time of designing the current study it was already known that research involving service users sometimes lacked a clear purpose and evidence generally about user involvement in research was hard to find due, partly, to poor reporting (Tarpey 2006). More recent studies have confirmed this (Staniszewska et al. 2011a; Staley 2009). It was known that service user involvement influenced the process of research, changed attitudes to research, broke down barriers, enabled shared experiences and power sharing, the formation of partnerships through empowerment and seeing a different perspective (Staley 2009).

During my experience as researcher and project manager for the LIMBIC project, I was involved in supporting the patient representatives in their role. Drawing upon my prior knowledge and experience of engaging with service users, I was aware of some of the potential difficulties about the process of service user involvement. Researchers encountered problems recruiting service users and difficulties were sometimes experienced by service users themselves in understanding their role. I became aware of new research findings about service users' expectations (Smith et al. 2006) which led me to develop an interest in learning more about how they experienced their involvement role, with a view to being able to gain new knowledge in this area.

1.5   Organisation of the thesis

This thesis is organised as follows:
- Chapter 2 provides an overview and analysis of the research evidence available at the start of the study which pointed to a gap in the literature and the subsequent development of the research question for the study
- Chapter 3 details the design of the study, the philosophical and theoretical perspectives and the methodology. Ethical considerations and research rigour are also discussed
- Chapter 4 presents the details of the thematic analysis and the emerging findings from each of the three stages of the study
- Chapters 5, 6 and 7 detail the progression of the thematic analysis and the presentation of the findings as themes
- Chapter 8 presents a new model for co-learning as an outcome of the study and discusses the relevance of the findings from the research study to the world of

service user involvement. It illustrates how this study provides insight into the experience of service user involvement and relates these findings to other current evidence.

- Chapter 9 provides conclusions of the study, the contribution to knowledge, the limitations and recommendations for future practice and future research.

This study draws on the wider LIMBIC project to address a need for further research about the experience of service user involvement. Few studies have worked with service users in the same way as the LIMBIC project. Service users were involved in a variety of ways and at different levels. Their involvement as research participants and co-learners with primary health care teams was particularly unique and those particular experiences are explored through this current study.

2.   Review of the literature

2.1   Overview of the evidence

Before embarking on this research study, I had previously engaged with some of the literature around service user involvement in previous roles recruiting and working with service users in health care organisations. As I began to explore the current evidence on service user involvement, it became clear that there was a vast body of literature using a range of terminology describing different levels and methods of service user involvement. As I tried to focus my research idea, trying to concentrate on a specific area of knowledge, I was repeatedly drawn into the wider literature on quality improvement, service user involvement in health research, service user involvement in health education, and service user involvement in health service planning and delivery. Deciding an approach to undertake a literature search was the first major challenge for this study.

From my initial experiences of working with the literature I was aware that not all the relevant evidence would be captured as it was known that studies involving services users were not well reported (Stewart 2008). Researchers reported their inability to locate the written material they required despite undertaking systematic and wide-ranging literature reviews (Paterson 2004). The review of evidence presented therefore is not exhaustive, but identifies the key themes from the research prior to 2008. This collection of literature guided the development of the research question and the design for this study. There has since been a rise in evidence around service user involvement in research, in health service delivery and in health education, some of which is drawn into this chapter by way of an update of the initial literature review and is also integrated into the discussion of the findings in Chapter 8.

Evidence showed that the details about service user involvement were often omitted from research reports and suggestions were made for future research to demonstrate the effectiveness of consumer involvement (Smith et al. 2009; Oliver et al. 2008; Nilsen et al. 2006; Smith et al. 2006; Telford et al. 2004; Paterson 2004; Chambers et al. 2004; Ong and Hooper 2003; Simpson and House 2002; Edwards and Staniszewska 2000).

Areas of literature that are covered in this overview are those of service user involvement in health research, health education and health care delivery published up to 2008, when the body of evidence for service user involvement was developing rapidly. To locate any studies in my area of interest I developed a strategy for a literature search limited by the traditional parameters of topic, population and time (Appendix 3). The search revealed a large volume of literature over the broad theme of service user involvement, not all of which was relevant to my research area. I therefore also carried out processes of browsing and berry-picking to try to locate the specific and more relevant literature (Bates 1989).

2.2   The rise of service user involvement

The concept of consumerism in health and general welfare was probably the consequence of a political shift with policy makers showing more interest in consumer choice and illustrating how politics was moving into the health care arena (Smith et al. 2008; Boote et al. 2002; Beresford and Wallcraft 1997). As public services continued to develop their consumerist approach, it became usual practice to engage people in the development of services as well as in the delivery and evaluation of these services (Social Care Institute for Excellence 2012; Department of Health 2010; Care Quality Commission 2009; Department of Health 2009a; Department of Health 2009b; Department of Health 2008a; Department of Health 2008b; Department of Health 2008c; Department of Health 2008d; Department of Health 2006a; Department of Health 2006b). Not only has health service delivery been developed to involve people who access services in its working practices, but education and research organisations also now endeavour to engage routinely with their service users. The last couple of decades have seen numerous developments for involving and engaging service users in the design, delivery and evaluation of services. Things have moved on. A large body of work now demonstrates the growth and potential impact of service user involvement in the work programmes of health, education and research organisations (University of Central Lancashire 2013; INVOLVE 2012; University of British Columbia 2012). The United Kingdom is believed to lead the world in its approach to formalisation of service user involvement at an organisational level (Spencer et al. 2011).

The breadth of literature about service user involvement is a reflection of the drive for improvement in quality of care across health care organisations. Throughout the several re-organisations that have taken place in the UK National Health Service over its sixty year history, an increase in promoting public involvement has featured, alongside the drive for professional accountability. Health and social care providers and academic institutions now routinely involve service users in service delivery, planning and evaluation and in policy development and priority setting (Nilsen et al. 2006; Smith et al. 2006; Oliver et al. 2004; Crawford et al. 2002; Boote et al. 2002). Social attitudes are more accepting of user involvement and there has been an increase in the amount of research reporting the involvement of patients and the public in health services. Evidence of the escalation of patient and public involvement studies over the last five years is illustrated for example by the several updates to the bibliographic library produced by INVOLVE (2012) from 85 references in Volume 1 in 2007 to 221 references in Volume 4 in 2012. Examples in this library are those pieces of work which contain critical analysis or substantial reflection on the nature of service user involvement as well as those illustrating new perspectives.

The aim for the Department of Health's five year strategy, Best Research for Best Health (Department of Health 2006a), was for a health research system focused on the needs of the patients and the public and followed earlier strategies which claimed to place user involvement centre stage (Ong and Hooper 2003). Engaging with patients and the public would make research more relevant to peoples' needs and more likely for the recommendations to be put into practice (Frankham 2009). Embracing the importance of user involvement was beginning to occur, but it was a long way from being embedded in everyday research practice. Batalden et al. (2009) called for action from those in management and education roles demanding new levels of cooperation among people from different disciplines and organisations. Some years later Thompson et al. (2012) reported patient and public involvement to be firmly embedded in health policy in England. Research proposals and calls for funding however, were still not always making clear their reasons for involving service users in the research. This might be because there is lack of clarity about why service user involvement should be encouraged or it could be because the evidence of impact of service user involvement is weak, ambiguous or unreliable.

Healthcare organisations have received support in their attempts to involve service users through the publication of national guidelines (NICE 2008) and through the establishment of quasi-independent watchdog organisations such as Patient and Public Involvement Forums in the early part of the new century, Local Involvement Networks known as LINks a few years later (National Centre for Involvement 2008) and more recently through local government Healthwatch organisations, all of which illustrate the importance placed upon service user involvement by government and health care leaders (Department of Health 2012; Hogg 2007). There is also a moral argument that service users should have a voice in research which may have an impact on their health status (Staniszewska et al. 2011b; Smith et al. 2008).

The literature offered descriptions of different levels of service user involvement, from those that were tokenistic at one end of a continuum, to those that embraced co-learning at the other (Nilsen et al. 2006). Others suggested sets of principles describing involvement activity (Dewar 2005; Smith et al. 2006; INVOLVE 2004; Telford et al. 2004; Tew et al. 2004 cited Spencer et al. 2011). INVOLVE describes three different levels of user involvement in research (Staley et al. 2012; Staley and Minogue 2006). See Figure 2.

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Levels of service user involvement in research

Consultation – where service users and carers are asked about their views on research, for example to comment on a research proposal, and then these views are used to inform decisions made within the project.

Collaboration – where service users and carers are involved as active partners in research, for example by working with researchers to design or undertake a project.

User-controlled research – where the locus of power, initiative and decision-making lies with service users rather than with professional researchers. This does not necessarily mean that service users undertake every aspect of the research or that professional researchers are excluded altogether, but it does place an emphasis on the transfer of power.

Figure 2. Levels of service user involvement in research

Whether hierarchy or continuum, the sharing of planning and decision-making responsibilities, effectively power-sharing, is crucial to what can be achieved (Henwood 2007; Frankham 2009). Arnstein's (1969) ladder of citizen participation is frequently cited as the model for describing the levels of service user involvement in research where a move from power-sharing, to a transfer of power to the service user is seen as the ultimate goal. Arnstein's model has also been much criticised because it restricts the potential contribution of service users due to its emphasis on the importance of who holds the power. Due to its linear structure and its lack of acknowledgement of the context, it fails to acknowledge all of what the service users have to offer and the value of the service user involvement process (Tritter and McCallum 2006). Suggestions have been made about drawing upon the diversity of what service users and health professionals or researchers can bring, which leads to them becoming co-producers of knowledge that can influence health policy and practice (Gillard et al. 2012).

Barriers to service user involvement include negative attitudes, credibility, time constraints, lack of resources, organisational boundaries, negotiation, collaboration and power sharing (Frankham 2009; Learmonth et al. 2008; Oliver et al. 2006; Dewar 2005; Oliver et al. 2004; Baxter 2001). Early studies have shown that power imbalances stood in the way of developing effective working relationships (Sullivan et al. 2001) and yet an awareness of power differentials and a desire to share power have actually been shown to facilitate lay involvement (Baxter et al. 2001). Good leadership is a key attribute that helps to overcome some of these barriers (Andersson et al. 2008; Oliver et al. 2004).

2.3   Exploring the impact of service user involvement

Involving service users in planning of health care can lead to more accessible and acceptable health services whereas involving users in research can lead to research that is of better quality, more relevant to patients, and of benefit to the users (Staley et al. 2012; Brett et al. 2010; Stewart 2008; Coulter and Ellins 2007; Nilsen et al. 2006; Smith et al. 2005; Telford et al. 2002) but if true patient involvement is being achieved, it is necessary to ask what its true impact has been (Cook 2012; Meyer 2000).

It was often argued that the impact of involvement of service users in research had not been evaluated sufficiently (Nilsen et al. 2006; Minogue et al. 2005; Ong and Hooper 2003; Simpson and House 2002) but a review of the literature in 2009 provided current evidence of the impact of public involvement in health and social care research (Staley 2009). The main challenges for this work had been in identifying the relevant articles, the limited amount of evidence of impact and the gaps in the evidence. Staley's review provided a broader evidence base for the impact of public involvement on health and social care research and showed public involvement to have had a major impact in qualitative research where participants were asked to share their views and experiences. It also highlighted where involvement had led to unexpected impacts and suggested these have been ignored in the past because of the emphasis on promoting public involvement. Staley (2009) suggested that evidence of all the findings, including those which are unexpected, should be reported as this would help to optimise user involvement in the future if researchers are more aware of the benefits and shortfalls of service user involvement.

User involvement can change researchers' attitudes to public involvement (Crawford et al. 2002) and act as a catalyst for establishing long term partnership working. According to Staley (2009), a positive impact is more likely when users receive training and support. Her review found that 'very powerful and convincing evidence can come from simply telling the story of involvement' (Staley 2009 p94). She suggested the interaction between researchers and the public helps researchers to focus on what is important for service users and that the best way to do this might be by asking for personal reflections on their involvement. One of the most frequent ways in which service users are involved in the teaching environment is when they are asked to tell their own story (Repper and Breeze 2007).

Benefits that can be achieved, for both service users and researchers, are around enhancement of their understanding of the issues, improvement in the quality of research and increased confidence in taking a participatory role (INVOLVE 2007a). Other benefits include the fact that research funding to undertake a study is more likely to be successfully achieved where high quality service user involvement is proposed and the findings of research may be seen as more credible to the public when a user perspective has been sought. Involving service users can help to ensure that the outcomes are relevant to service users, that research is of higher

quality than if it were undertaken without service user input (Cornwall and Jewkes 1995) and that it genuinely benefits the people it intends to help (Frankham 2009; Canadian Health Services Research Foundation 2009; Staley and Minogue 2006).

User involvement can break down barriers, lead to shared experiences, build understanding and seek diversity of knowledge (Tritter and McCallum 2006) from a range of settings (Patterson 2004), individuals, groups (Tarpey 2006) and organisations (Smith et al. 2008) and as other have indicated this has the potential to create the setting for co-production to occur (Boyle and Harris 2010). Co-production is the process where clients work alongside professionals as partners in the delivery of services (Boyle et al. 2006). Co-production is seen as a goal of service user involvement because it is where knowledge is produced across disciplines, it includes lay people and is similar to research approaches such as participatory action research and community based participatory research (Gillard et al. 2012). In co-production initiatives, the diversity of knowledge and the experiential knowledge of service users and health care professionals make significant contributions to the process (Barnes and Cotterell 2012; Thompson et al. 2012; Lowes et al. 2010; Boyle and Harris 2010; Bovaird 2007; Tritter and McCallum 2006; Skidmore et al. 2006).

Drawing together a group of service users who are then expected to work together might work well, but this is not always so (McKeown et al. 2012; Caldon et al. 2010). There are aspects that will enhance the success of the project if the service users and the team cohere and function well. Conversely, there might be disappointing consequences if it does not. Research teams can offer different ways of engagement for service users (National Institute for Health Research/Mental Health Research Network 2012; Baxter et al. 2001).

Managing the expectations of service users is a further challenge, and because service user involvement does not necessarily lead to service improvement, successes in patient involvement are also difficult to define (Fudge and Wolfe 2008, Oliver et al. 2004). The Cochrane review of involvement of consumers in developing healthcare policy and research, clinical practice guidelines and patient information suggested the effects of consumer involvement were "largely unevaluated" (Nilsen et al. 2006, p10). Despite a broad inclusion criteria based upon the reviewers' expectations of low numbers of comparative evaluations in this area of consumer

involvement, only five studies in total were identified for inclusion in the review. The reviewers concluded that randomised controlled trials of consultations with consumers were feasible but they were left uncertain about the appropriate methods for involving consumers, suggesting that further trials were necessary.

The literature evaluating impact of service user involvement holds some convincing evidence, but there are weaknesses. Health care organisations and educational institutions have struggled to demonstrate the value of service user involvement in their research. Some critics emphasise the need for caution when considering involving lay people in strategic education work programmes for example (Stacey et al. 2012). In the United Kingdom, the reactive behaviour of government bodies in response to the serious consequences of health professionals acting below their professional standards, and sometimes illegally, has brought service user involvement into the mainstream. The regulatory bodies that have evolved since the turn of the century and following several high profile serious investigations and inquiries, such as the Bristol heart surgeons, Professor van Velzen at Alder Hey Hospital and general practitioner Dr Harold Shipman made explicit the requirement to involve service users at all levels in the work of health care organisations (Kennedy 2001; Redfern 2001; Smith 2005). Legislation in 2007 charged Primary Care Trusts with the duty to involve service users and to report on their involvement as a requirement of UK law and became statute through the Health and Social Care Act in 2008. The limitations of the effect of these changes are illustrated in the recently reported dehumanisation of large numbers of patients in the care of Mid Staffordshire Hospitals NHS Foundation Trust (Francis 2013) which leads us to question the purpose of the legislation and the quality of the regulatory processes.

2.4   Motivations and expectations of service users

The literature reveals common themes related to the reason most service users become involved in research. These are around the desire to influence and improve services and about having their voice heard (Cotterell et al. 2008). Some of the service users who get involved in research, say that they do so because it gives them a voice and that it allows them to influence the processes that affect peoples' lives. They wish for others to benefit from their involvement by influencing change (Wyatt et al. 2008; Tarpey 2006). For service users, involvement can provide:

> "…a positive channelling of the frustration and anger
> personally experienced by people who feel badly treated by
> health and social care services and research…"

<div align="right">(Tarpey 2006, p13)</div>

Service users also learn about the research process and are able to share advice and provide support for each other (Minogue et al. 2005), with some even becoming credible experts (Thompson et al. 2012). The concept of credible expert has been challenged in the more recent literature with suggestions that the "professionalisation" of service users renders their position to one that is similar to the health professional in terms of their knowledge about a subject (El Enany et al. 2013, p24). Arguments about the paradoxes of involving service users in healthcare are around the training of lay service users leading to them becoming experts (Ives et al. 2012) and the attempts to mould lay service users' interests and expertise whilst omitting to take note of what it is they bring to a study because of who they are (Lehoux et al. 2012a). Adding to the complexity of views, some researchers argue that because service users are not researchers, involving them in research can compromise the rigour of the research (Thompson et al. 2009).

Motivations for getting involved in research arise from an interest in "having a say" and in influencing the processes that affect peoples' lives (Tarpey 2006, p13). Being involved in research can increase people's confidence and understanding if the research is well planned and resourced (Tarpey 2006). The experience of being involved in research may give those who become involved the chance to turn a negative experience into something of potential benefit to others (Paterson 2004), it may be about being part of something worthwhile (Faulkner 2004), or about wanting to leave a legacy or influencing research for the benefit of others (National Centre for Involvement 2009a; Frankham 2009; Barnard et al. 2005; Cornwall and Jewkes 1995).

When a research team assumes the service user is merely a recipient of health care who is incapable of comprehending concepts related to research, this can lead to goals not being achieved, described by Renedo and Marston (2011, p273) as:

> "…a representation anchored in images of involvees as
> lacking skills and struggling to function in expert-institutional
> contexts."

The research team can have an influential role in the service user experience by taking a proactive approach to maintaining the motivation of the participants. Whilst this is a continuing challenge, it is necessary as motivation of the participants has an impact on the success of the project and its outcomes (TwoCan Associates 2011).

It is possible to provide service users with information about the range of expectations that they might experience, alongside information about potential problems or pitfalls, such as learning something about their condition that they may not have wanted to hear. Story-telling, for example, can have a negative impact if people hear upsetting stories (Barber 2011a; Pandya 2010; Broad and Saunders 1998). This could discourage researchers from using such approaches, but they need to be prepared for a range of consequences. Others have seen service users report the development of a coherent illness narrative which gives them new insights into their problems and deeper understanding of the doctor-patient relationship (Walters et al. 2003).

Service users are a valuable source of untapped experiential knowledge that allows them to bring an informed consumer perspective to the research process (Patient and Public Involvement Solutions 2009; Saunders et al. 2007, Cornwall and Jewkes 1995). The experiential knowledge of consumers encourages the asking of questions that health professionals may not have considered (Tritter and McCallum 2006) and working with different interpretations of the same data may provide new lines of inquiry within a study (Trivedi and Wykes 2002). Service users have also been reported as having an evaluative function in relation to the research in which they engage (Thompson et al. 2012). The service users therefore become research tools along with the researcher.

Whilst lay people might lack in-depth, specialist knowledge about research, professionals might lack critical knowledge about a condition or a setting (Tritter and Mcallum 2006; Baxter et al. 2001; Entwistle et al. 1998). As owners of their own knowledge and a "hidden resource" (Boyle and Harris 2010, p3), lay people bring their experiential knowledge therefore helping to maintain the focus of a given research project (Beresford 2007) and facilitating knowledge exchange in their role as knowledge brokers (Armstrong et al. 2013).

User involvement has been described as the process used by public bodies to create empowerment opportunities for their communities (Patient and Public Involvement Solutions 2009; Ellis and McIver 2009; Frankham 2009; Henwood 2007; Cornwall and Jewkes1995). Promoting equal partnerships between patients and those working with them is an important way of gaining their meaningful involvement (Esson et al. 2009; Andersson et al. 2008; Dewar 2005; National Health and Medical Research Council of Australia 2004; Hudson 2002; Department of Health 1998). Those arguments which support the creation of genuine partnerships, where both parties have equal say, claim they are most effective when the relationship between consumers and researchers is an active process where a two-way dialogue in the research process gives way to involvement at all levels (Walter et al. 2003, Boote et al. 2002; Sullivan et al. 2001). Other researchers argue that real partnerships, where both parties have equal say and equal power to influence, are rarely achieved (Abma 2005; Ong and Hooper 2003).

Motivations for healthcare organisations to involve service users might reflect their response to regulatory requirements. The process of service user involvement has become bureaucratised by making healthcare organisational management teams responsible for demonstrating their service user involvement processes to their boards and regulators. This systematisation of service user involvement, however, may have led to tokenistic approaches to involving service users and failure to undertake effective strategies for involving service users. The purpose of involving service users seemed to get lost along the way.

In addition to the arguments about tokenism, it has also been suggested that, although researchers might ask patients about what is important to them, they do not necessarily act on what patients say (Leatherman and Sutherland 2007). It is often not whether the patient or their representative will make a comment, contribute to the debate or offer feedback but whether their contribution will be heard or acted upon by those who are supposed to be listening. For patient participation to be both effected and effective, there needs to be a change in the mind-set of many healthcare professionals, for example from the expert doctor model to one focussed on patients; what Abma (2005, p1326) describes as "a cultural revolution in health care." In support of Abma (2005), other researchers suggest that developing and sustaining community and consumer participation requires change in the structures

and attitudes, which take time and commitment (Spencer et al. 2011; Reeves and Seccombe 2008; Saunders et al. 2007).

Some of the studies describing the process of involvement have made suggestions about the provision of practical support and reimbursement, backed up by feedback and skills training suggesting that this helps people to act on and develop their motivations for involvement in research (Saunders at al. 2007; Tarpey 2006; Hewlett et al. 2006). Training at the start of a project, support from the leading team, support from peers and mentoring are all known to benefit those who engage as service users (Faulkner et al. 2012; Rhodes 2012; Sweeney et al. 2012; Barber et al. 2011b; Boyle and Harris 2010; Pandya 2010; Caldon et al. 2010; Brett et al. 2010; Lowes et al. 2010).

Careful planning of the recruitment process, or when first "making connections" (Morrow et al. 2012 p60), is an essential part of preparing service users for their role and in facilitating their involvement so that true partnerships can flourish (Armstrong et al. 2013; Caldon et al. 2010; Basset et al. 2006). Role descriptions, information packs, reimbursement of travelling costs, buddy systems, flexibility, time and an open approach from the project workers are all part of the supporting infrastructure that can help to contribute to successful recruitment and continued engagement (Katz et al. 2012; Caldon et al. 2010; Baxter et al. 2001).

Teams need to feel able to show trust and mutual respect for people with different views and experiences if they wish to work together productively (Aveling et al. 2012; National Institute for Health Research 2012a; Craig 2008; Smith et al. 2006). Preparation of the environment means taking considered approaches about place, culture, rules and language.

There will be consequences when adequate support for service users is not provided. From the service user point of view, a lack of sufficient information about the study could lead to them failing to engage, not understanding the principles of the study or trying to achieve things outside of the scope of the study. This could result in feelings of regret, disappointment or failure; they might feel they "gave more than they gained" (Lauckner et al. 2012, p998; Rhodes et al. 2002). It also demonstrates a lack of respect for the service user on the part of the project team if they are unable to provide sufficient information about the study at the recruitment

stage (Basset et al. 2006). It is useful for service users to be offered a range of types of support such as on-line, face-to-face, email, phone contact and written material. Service users could also be given the opportunity to state their preferences for accessing support.

Establishing the ground rules for the working relationship helps to create the right environment for co-learning (Morrow et al. 2012; Barber et al. 2011b) and taking a proactive approach towards on-going support should be an integral part of the study protocol (Mosconi et al. 2012; Minogue et al. 2005). Diverse strands of support can be offered; a named lead individual or a service user champion (Faulkner 2004), but a balance needs to be achieved whereby service users are provided with sufficient appropriate information whilst not becoming too dependent on the research team for guidance, hindering their potential for asserting their influence at the appropriate time.

There is no recommended right approach to service user involvement in research and an array of approaches have been utilised to create an environment which is conducive to learning for people from differing backgrounds (Greenhalgh et al. 2011; Nilsen 2006; Paterson 2003; Beresford 2003; Van Wersch and Eccles 2001; Ryan et al. 2001; Entwistle et al. 1998). Moving away from traditional methods might be of benefit such as holding stakeholders juries instead of paper-based consultation exercises (General Social Care Council 2012).

To summarise, the literature illustrates a breadth of evidence with widely conflicting opinions about the involvement of service users in health service research. There is rich debate about impact, agreement about lack of clear purpose and examples of tokenism, but no sensitive acknowledgement to the person who was the service user. There is agreement about there being no best way or right way for researchers and consumers to work successfully together (Greenhalgh et al. 2011), but that it is necessary "to take small steps to go a long way" (Paterson 2003, p160). In her later research, Paterson (2004) explored the reflections of participants involved in clinical research around complementary and alternative therapies and gave an example of a consumer representative from a charitable organisation indicating surprise about "how little the rest of the team knew about the experience of living with back pain" (Paterson 2004 p156). Pointing directly to the study

population of the LIMBIC project, this finding from her research led eventually to the conception of the research question for this study.

2.5   New areas of service user involvement

The impetus for involving service users and carers in health and social care education followed the drive to involve service users and carers in the provision and delivery of health services (Department of Health 2002b, 2006c) which responded to the increasing consumer focus in health and the findings from public inquiries into health service failings. Professional bodies and government policy have made it a requirement for higher education institutions to demonstrate involvement of service users and carers in education and training for social workers and for health professionals (Department of Health 2002b).

There has been an increase in the number of studies of service user involvement in higher education institutions over the last decade driven largely by service users themselves, the professional bodies and government policy (Chambers and Hickey 2012). The Department of Health Education Commissioning for Quality document (2009) includes guidance on user involvement in the design and delivery of education and the Nursing and Midwifery Council now requires evidence of involvement in programme development and delivery (Nursing and Midwifery Council 2010; Rhodes and Nyawata 2010). The Health and Care Professions Council (2012a) have developed Standards of Education and Training (SETs) for service user involvement in the design and delivery of their regulated education and training programmes. Methods of involving service users the education of health professionals includes their involvement course design, student assessment and teaching in the classroom (Cooper and Spencer-Dawe 2006; Repper and Breeze 2007; Haeney et al. 2007; Thomson and Hilton 2011).

In 2003 when the educational requirements for a social work qualification changed from a diploma to a three-year degree course there was also a requirement for higher education institutions offering the degree to involve service users and carers in the design and delivery of the programme. This is illustrated by their involvement in recruitment and selection of students for the social work degree programme, involvement in teaching programmes and in the assessment of learning. It is now

usual practice for service users and carers to be involved by helping to design the interview process and they might also be involved in undertaking the interviews for social work degree placements (Department of Health 2002b; General Social Care Council 2005).

Methods for the involvement of service users and carers involvement in social work teaching might take place through the sharing their personal stories as case studies or they might be presented in the form of digital recordings such as video. Service users and carers are also involved in assessment processes and they might also be involved in programme design or in the recruitment and selection of academic staff.

Drivers for service user involvement in social work education programmes were found to be similar to those in the health sector – that is demands from service user-led organisations and regulatory requirements. The values of social work staff in universities were also found to influence the drive to involve service users in their education programmes (Robinson and Webber 2013).

Some have reported a lack of evidence in the literature of the process of service user and carer involvement in education and training generally. A recent review which explored the literature between 1993 and 2010 around the issues of service user involvement in the assessment of students' practice (Gray and Donaldson 2010) concluded that the consensus was to involve service users and carers in the formative feedback (or review) of students in the practice setting. The use of protocols and structured easily understood and implemented tools are recommended as is the inclusive and appropriate level of engagement training for all stakeholders involved in the process.

Research evidence for the impact of service user involvement in social work education is minimal with suggestions of a dearth of research around the involvement of service users in post qualifying social work programmes (Robinson and Webber 2012). This finding reflects similarly to that of Spencer (2010) whose review showed little in the amount of research of service user involvement in the education of doctors or health care professionals generally in their continuous professional development (CPD) programmes. The majority of research around service user involvement in education is in undergraduate programmes (Carr et al. 2012; Morgan and Jones 2009). There is little research around service user

involvement in post graduate education which is the setting for this current study, that is primary health care qualified practitioners and their teams.

It has been argued that successful service user involvement in education programmes is that which impacts the relationships between those working within health and social care services and those who use health and social care services. Ultimately this might lead to a deconstruction of the way illness is perceived and bring new understandings which discard the concept of disadvantage that is usually associated with illness (McKeown et al. 2010). Further exploration of these suggestions is required.

2.6   Exploring the service user perspective

At the time of designing this study a small number of studies had tried to explore the experiences of service user involvement in research (Smith et al. 2006; Crawford et al. 2002) seeking reflections as projects drew to a close and prompting service users for written feedback. Other researchers have reported the experience of involvement describing empowerment, support, communication and motivation (Barnard et al. 2005) and researchers are being encouraged to focus more on what it is like for those who become involved (Harlow and Morris 2009). Faulkener (2004) offered users the opportunity to reflect on their personal experience and Sullivan et al. (2001) attempted to understand the perspectives of both researchers and community members on their working relationships. Well over a decade ago, Bastian (1996) declared a lack of sufficient literature on peoples' experiences.

Reflecting on patient involvement in healthcare, Edwards and Staniszewska (2000) described the quest for understanding the users' perspective as hopeless. They suggested that researchers should accept the difference in perspectives proposing that this was a step towards a better understanding. More recent research exploring the experiences of partnerships in research reveals a need to address the issues of gaining trust and listening (Staley at al. 2012; National Centre for Involvement 2009a; Boote et al. 2002; Baxter 2001). Researchers should not underestimate the complexity of the responses given to them by users or assume that they have detected all that the users have to say or what they are feeling (Edwards and Titchen 2003; Edwards and Staniszewska 2000). This is difficult in any context but

an important concept that I aimed to keep in mind during the process of this research. Edwards and Titchen (2003) led me to deeper thinking about the methodological approach for the study I was to undertake, inviting me through their work to seriously consider the phenomenological sociology approach and other approaches that were similar and more appropriate.

More recent studies have gone further in exploring the service user experience (INVOLVE 2013; Shippee et al. 2013; Fischer and Ereaut 2012; Staley 2012; McKeown et al. 2012; General Social Care Council 2012; National Institute for Health Research 2012a; Quinlan and Robertson 2010; Staley 2009; Cotterell et al. 2008; European Patients' Forum 2008; Staley 2007; Tarpey 2006; Barnard et al. 2005 and Thornton et al. 2003). Other researchers have observed the value of service user initiatives where learning together is a key feature (Cook 2012; Barber et al. 2011b; Telford et al. 2002; Hanley et al. 2001; Oliver et al. 2001).

2.7   Methodologies for service user involvement research

Since the turn of the century there have been significant shifts in the literature on service user involvement. In response to changes in the law through the Health and Social Care Act (HM. Government 2003) and subsequent research policy (Department of Health 2006a) research funding bodies now make service user involvement an explicit requirement for research proposals and in making their awards. The increase in literature about service user involvement in research which resulted has boosted the debate about the perceived impact of service user involvement leading to arguments developing about its true value. The debate about barriers to involvement built rapidly and arguments about the tokenistic approach towards service user involvement taken by some researchers dominated the literature for some years and still do to some extent today. Some refer to the involvement of patients in influencing change as 'the patient movement' where they are referred to as radical activists because they speak up for patients who are ill-treated by those in positions of power (Williamson 2010, p34). Evidence still supports the fact that there is little formal evidence of the effects of service user involvement (Kreis et al. 2012).

There has also been recent resurgence of the debate about how and whether patients or service users can be representative of a particular service user

population. The counter argument accuses service users of going native or becoming experts in their own field and therefore unable to provide a lay perspective any more. This has led to a further debate about whether service users are invited to join a research team to support them or to challenge them in their decision processes. The research has followed the legislative processes which have governed the delivery of NHS health care and have contributed to the increasing evidence base which has led to the undertaking of research using a variety of approaches and methods. This however has not led to any consensus about which research approaches are most suited to service user involvement. There have been a number of theoretical and methodological models and frameworks for research involving services users. Research approaches remain many and varied. This is not necessarily a problem for the body of convincing research evidence, but it means that researchers, especially those who are new to research about service user involvement may struggle to find a methodological approach that fits well with their research question.

Several researchers agree that there is no single recommended approach for research involving service users (Greenhalgh et al. 2011; Doel et al. 2007; Paterson 2004) and studies have used qualitative, quantitative and mixed methods approaches. As a methodology used to study human experiences, a qualitative approach is appropriate for exploratory studies involving service users using small samples in order to gain depth of insight into peoples' experience and possibly also involve them as research participants (Morrow et al. 2012).

Acknowledging the competing views about the validity of research evidence for service user research, Beresford (2007) stressed the importance of seeking the views of service users about what contribution they think they can make. This could be about involvement in conventional research projects, collaborative research, emancipatory research or survivor research. He went on to suggest that positivist approaches to service user involvement research can act as barriers to service user research. Some researchers have gained useful knowledge using quantitative methods and others have used mixed method or multi-method approaches (Oliver et al. 2008; Wyatt et al. 2008). Hill (2011) proposed a conceptual framework for communication and participation in health which combined scientific approaches and democratic participation at all stages of health policy and service improvement.

Others suggest that it is necessary to rethink research as co-production of knowledge. In their mental health study, Gillard et al. (2012) described a reflexive process of collectively constructing knowledge as a methodological solution to analysing qualitative interviews when the face to face validity of the data is hard to establish. The Patient Centred Outcomes Institute (PCORI) called for proposals in patient-centredness research to include those that identified optimal methods for engaging patients in the research process (PCORI 2012). The importance of recognising the links between context, mechanism and outcome are considered equally important in undertaking and interpreting research involving service users (Staley 2012; Aveling et al. 2012; Brett et al. 2010; Pawson and Tilley 1997).

Participatory action research has been promoted by some researchers for undertaking service user involvement (McKeown et al. 2010; Marlett and Emes 2010; Abma 2005; Aranda and Street 2000). User controlled research can fill gaps that might be left by other research approaches (Beresford 2007). Qualitative case study approaches have been used successfully by Wyatt (2008), Abma (2005) and Lindenmeyer et al. (2007), the latter also using a partnership approach which involved service users as co-evaluators (Doel et al. 2007). Ethnographic studies (Armstrong 2013; Renedo and Marston 2011) and grounded theory (Rutherford 2011) are a few of the many approaches that have been used to explore service user involvement. Grounded theory is an appropriate research methodology when the topic has not been previously studied and where new perspectives are required to fill a gap in our understanding of the issue.

Research methods that are used in qualitative studies are those which use instruments such as questionnaires, checklists and interview prompts to collect the data and includes the researcher as a research instrument. Data collection methods include interviews such as semi-structured interviews (Pickard et al. 2002), peer interviewing (Godfrey 2004; Broad and Saunders 1998) and interviews with staff Gutteridge and Dobbins 2010). Reviews of documentary evidence (Attree et al. 2011; Wyatt 2008; Pickard et al. 2002) document retrieval or audio-visual data retrieval and analysis often takes a thematic approach with the researcher placing interpretation on the data from the thematic analysis. Attempts have been made to explore perspectives with a view to developing consensus around appropriate methods for user involvement (Daykin et al. 2004) and others suggest that pluralist

approaches using a number of different methods can help to ensure that the evaluation is broad based and had internal validity (Doel et al. 2007).

Aranda and Street (2000) used narratives in a participatory research process to develop new insights and Blickem and Priyadharshini (2007) explored the educational potential of patient narratives for improving patient-centred interprofessional care. An unexpected benefit of the narratives was the way they created the conditions for an exploration of the patient perspective. In contrast to a structured type of approach, the open-ended nature of stories can allow room for recognising the complexity and ambiguity of perspectives, roles and interactions. Observation (Armstrong 2013; Renedo and Marston 2011) and web based survey approaches (Katz et al. 2012) towards service user involvement evaluation have also been used.

In addition to the methodology and methods, it is also generally agreed that the theory and philosophy of public involvement in research and education is lacking and needs development (Stewart and Oliver 2008; Rees et al. 2007). Theory has been shown to be lacking but when is does exist, theoretical perspectives vary widely. Complexity theory underpinned an interprofessional education intervention study where the researchers found that trying novel methods of learning aided learning about complex systems (Cooper and Spencer-Dawe 2006) and Aveling's (2012) critical interpretive synthesis study was based on theory of change.

The challenge in undertaking research which involves service users includes complex and broad ranging literature and lack of consensus about how best to approach, undertake and underpin the research with theory. An approach is often required which reflects the nature, sources and types of data that are involved.

2.8   Developing the research question

The literature search revealed a gap in the reporting of research around user involvement particularly about the experiences of service users involved in research. The history of research around user involvement revealed a continuing increase in research involving service users from its initial onset with the advent of consumerism as part of a political shift and pointed to some of the barriers to service user involvement and some reporting of measures used to support the

process of service user involvement. The research around impact of user involvement continued to dominate much of the literature until a review by Staley in 2009 drew together the evidence around many of the contentiously debated issues. As the literature continued to focus largely upon the impact of user involvement on the research process and research outcomes, there seemed to be minimal interest in the impact of being involved, or the experience of being involved on the service users themselves. Further exploration of the literature revealed some anecdotal evidence about the service user experience often as part of the reflective processes as research was being completed. The experience of service user involvement, from the service user perspective appeared to be an area that was largely ignored.

Table 1 on pages 40 to 44 identifies the evidence from the literature which led to the development of the research question for this study.

Focus of the strand from the literature	Reference	Key points	Contribution to Research Question
General overview of the evidence of research about service user involvement	Edwards and Staniszewska 2000, Ong and Hooper 2003, Paterson 2004, Smith et al. 2006, Smith et al. 2008, Oliver et al. 2008.	• Details about consumer involvement were often omitted from the published papers. • Further research was required to demonstrate the effectiveness of user involvement. • Formal research of public involvement was rare.	• These papers helped in refining the initial ideas for this study by identifying the paucity of research about the service user experience. • The gaps which were drawn out through these papers helped me to develop the research question for this study. • These papers described some examples of good practice in service user involvement such as the provision of training and support but they failed to address the need for understanding the experience of the service user.
	Chambers et al. 2004	• Few researchers were aware that involving service users could benefit health research. • Suggestions were made that with training and support, service users could form groups or networks which could provide input to the research process.	
	Oliver et al. 2006	• A framework was used to identify gaps in the literature which showed a lack of studies around the different degrees of involvement, forms of communication, involvement in decision-making and the provision of training and support for service users.	
	Telford et al. 2004	• Involving service users was shown to lead to better quality research and was more relevant to patients and of benefit to service users. • When service users and researchers or health professionals learn together, this brings value to the study. • The study went some way towards deepening the understanding of service user involvement in research, from the researcher perspective.	

Focus of the strand from the literature	Reference	Key points	Contribution to Research Question
The rise of service user involvement	Smith et al. 2008	• Increase in consumerism as part of a political shift	• These studies illustrated a lack of evidence about the service user perspective or the service user experience.
	Boote et al. 2002	• Increasing consumerism was bringing politics into health. • Genuine partnerships are more effective when there is an active relationship and there is involvement of service users at all levels. • Research is of greater quality and clinical relevance.	• Although there was a growth in the number of studies reporting service user involvement there was no evidence to suggest that the experience of the service user could be of importance to the research.
	Oliver et al. 2001	• Social attitudes now more accepting of service user involvement.	
	Beresford and Wallcraft 1997	• Concept of consumerism and the political shift.	
	Hogg 2007	• Importance of user involvement nationally.	
	NICE 2008	• National guidance on involving service users was made available.	
	Daykin et al. 2007; Green 2007.	• Increased service user involvement in health services.	
	Ong and Hooper 2003	• Time to place user involvement centre stage. Real partnerships are rarely achieved.	
Exploring the impact of user involvement	Abma 2005	• Real partnerships are rarely achieved.	• Some of these papers reported on the processes that could be used to help create the conditions for undertaking service user involvement such as partnership working. In so doing they recognised that the conditions were an important part of the process.
	Baxter 2001	• A desire to share power can facilitate lay involvement.	
	Sullivan et al. 2001	• Genuine partnerships are more effective when there is an active relationship and there is involvement at all levels.	
	Hudson 2002; Dewar 2005; Andersson 2008.	Promoting equal partnerships between patients and those working with them is an important way of gaining meaningful involvement.	• The concept of using reflection was recognised and included service users (Oliver 2004). This was of interest as reflection was being used by
	Oliver 2004	• Good leadership, investing time and effort in good communication, training and support so	

Focus of the strand from the literature	Reference	Key points	Contribution to Research Question
		that good working relationships could build can all facilitate service user involvement. • Research should also involve consumers reflecting on and reporting the process and outcome	participants (including patient representatives) in the LIMBIC project. • Some research showed how benefits can be gained from learning together and this was occurring with the participants in the LIMBIC project. • Some of these papers influenced the design of the research undertaken in this study by illustrating the relevance and value of using a narrative approach with service user research.
	Boyle et al. 2006	• Co-production was described as the process where clients work alongside professionals as partners in the delivery of services	
	Coulter and Ellins 2007	• Involving service users leads to research that is of better quality, more relevant to patients and of benefit to users, can improve quality, efficiency and health outcomes	
	Staley and Minogue 2006	• Involving service users leads to research which genuinely benefits the people it is intended to help	
	Tritter and McCallum 2006	• User involvement could break down boundaries, allow participants to share their experiences, build understanding between participants and seek diversity of knowledge and experience.	
	Oliver et al. 2001	• Observed the value of service user initiatives where learning together is a key feature.	
	Cooper and Spencer-Dawe 2006	• Interprofessional education intervention study tried novel methods of learning which aided learning about complex systems.	
	Aranda and Street 2000	• Narratives in participatory research developed new insights.	
	Blickem and Priyadharshini 2007	• Explored the educational potential of patient narratives for improving patient-centred interprofessional care	
Motivations and expectations of service users	Cornwall and Jewkes 1995	• Reasons for getting involved may be about wanting to influence research for the benefit of others.	• These studies influenced the research question for this current study as they illustrated how gaining an understanding of

Focus of the strand from the literature	Reference	Key points	Contribution to Research Question
	Paterson 2004	• The experience of being involved in research may give those who become involved the chance to turn a negative experience into something of potential benefit to others.	some of the motivations for service users getting involved in research, could lead to a better understanding of the experience of being involved, especially, for example when expectations were not met.
	Tarpey 2006	• Reasons for getting involved; others may benefit, gives them a voice, allows them to influence processes.	
	Stewart 2008	• Challenges in managing expectations of service users.	
	Fudge and Wolfe 2008	• Managing the expectations of service users is a further challenge, and because service user involvement does not necessarily lead to service improvement, successes in patient involvement are also difficult to define. • Professionals control the interpretation of involvement and this could impact upon the ability of user involvement to bring about change.	
Exploring the service user perspective	Beresford 2003	• What is reported tends to be the positive aspects of their experiences. He suggested that the exploration of user involvement in research should be given much greater priority on the social policy agenda.	• Some studies were beginning to suggest that further exploration of user involvement was required including that of the experience of involvement. A few studies were reporting reflective or anecdotal findings about the experience of service users who were involved in research processes. This led to the development of my research question of addressing the service user experience as the main study question.
	Telford et al. 2004	• Few describe the experience of patient involvement in research from the patient perspective.	
	Faulkener 2004	• Current evidence lacks detailed exploration of the experience of involvement	
	Beresford 2007	• Stressed the importance of seeking the views of service users about what contribution they think they can make. This could be about involvement in research planning, collaborative research, emancipatory research or survivor research.	• The service users I would approach had uniqueness in their role working with primary health care teams because;

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Focus of the strand from the literature	Reference	Key points	Contribution to Research Question
	Staley 2009	• Current evidence lacks detailed exploration of the experience of involvement, is limited to impact or effectiveness and barriers to involvement.	- None of the participants had worked together in such a project before, - Studies involving service users in primary care education were absent from the literature, especially in relation to quality improvement and back pain as part of the education initiative.
	Smith et al. 2005	• Members of the service user reference group were asked to feed back their views about their experience. • Limited evidence of benefit of service user involvement. • More work is needed to explore the meaning and importance of user involvement in research. • There may be benefits to service users. • It is essential we learn about service users' feelings about the process of being involved. • No evidence of research to show service users being involved in using the findings of research to influence change.	
	Smith at al. 2008	• Further research is required to demonstrate effectiveness of involvement. • There is a moral argument that service users should have a voice in research that will impact their health status. • Negative experiences are not reported because of organisational pressure on those being encouraged to engage with service users in research.	
	Minogue et al. 2005	• Patient involvement simply brings a different perspective. • Feedback on their experience of being involved is critically important.	

Table 1. Impact of the literature on the development of the research question

In addition to these studies there was a small number of systematic reviews which incorporated studies about service user involvement (Crawford et al. 2002; Simpson and House 2002; Oliver et al 2004; Smith et al 2006 and Nilsen et al. 2006). None of these reviews identified studies that had solely explored the area of service user involvement from the service user perspective. Studies that were reviewed focussed largely on the impact of service user involvement on the research outcomes and the processes for service user involvement in research.

This summary of the literature which led to the research question for this current study identified that previous studies gave minimal acknowledgement to the service user perspective when engaging with them in research. This new study would address that gap by developing a piece of research that would give them a voice about their experience of being involved in research.

The literature available at the time of developing the research question in 2008 and 2009 revealed no studies which focussed on what it was like to be involved in health research, from the perspective of the patient or service user. The timeliness of Staley's report (2009) pointed to this research area as relevant. It was therefore worthy of exploration with the service users from the LIMBIC project with a view to being able to gain new knowledge in this area.

The literature pointed to areas of potential relevance, including service users' motivations and expectations of engaging in research, the sharing of their views and experiences, their perceived experiences of empowerment and gaining confidence and what it meant to be involved in research in a service user role. The question of how well a partnership approach was taken in the LIMBIC project and whether this impacted on the experiences of the patient representatives was also considered. It might also be relevant to explore the provision of support systems as perceived by the patient representatives of the LIMBIC project and whether this contributed to their experience of user involvement.

Current knowledge about the involvement of patients as collaborators and partners in primary care research lacks detailed exploration of their experience of involvement and is limited to the impact or effectiveness of involvement and the barriers to involvement (Staley 2009; Faulkner 2004). A few researchers had begun to describe the experience of patient involvement in research (Smith et al. 2006;

Telford et al. 2004) and further research has since followed (INVOLVE 2013; Barber et al. 2011b; Pandya 2010; Cotterell et al. 2008). Before this current study began, it appeared that researchers omitted considering the impact of being involved on the service users, or they may have assumed that there was little that we did not know about being involved from the service user perspective. This new study will build upon the emerging evidence base. A distinct gap in that more recent evidence was about the experience of service user involvement in the learning environment with primary health care teams.

Born from my involvement in the LIMBIC project where I had been involved in seeking feedback from the patient representatives, expecting that they might be able to provide insight into their experience, I developed a research question to explore:

> What is the experience of service users who participate in interprofessional education research with primary health care teams?

The primary aims of the study were:

1. To contribute to the development of a body of knowledge about the experience of patients involved as equal partners with healthcare professionals from primary health care teams in an educational initiative and

2. To inform future service user involvement processes and future evaluative primary care educative interventions.

The following objectives addressed the study aims:

1. To explore the extent to which the aims of the LIMBIC project, in relation to patient involvement, were met

2. To explore the experiences of patient representatives involved in a specific primary health care research project

3. To analyse the existing data from the LIMBIC project that reflected the patient representatives' experiences and undertake further analysis where relevant

4. To analyse the extent to which user involvement processes had an impact on the LIMBIC project outcomes

5. To integrate new and existing findings to produce an account of the patients' experiences and the features of those experiences that might be relevant to future service user involvement.

Contribution to knowledge

The study offers new insight that deepens our understanding in relation to:

- user involvement in interprofessional learning in the primary care setting
- the experience of user involvement from the service user perspective
- the experience of service users in interprofessional education as part of a research process
- the experience of user involvement in quality improvement learning.

A picture of the current evidence for this study had been drawn exploring the literature that brought to light the current thinking around service user involvement. A gap was demonstrated in the evidence that was largely unexplored. A study design was required that would best address the research question and create the opportunity to seek new knowledge about the experience of service user involvement in quality improvement interprofessional learning.

3.   Research Design

The study design takes account of the larger evaluation project from which this study was developed, the LIMBIC project. Although the LIMBIC project did not specifically set out to explore the experience of the patient representatives, embedded within the data were details about their experience of their engagement with the project which could make a contribution to this current study. This chapter details the processes used for undertaking the research, the chosen methodology and methods, the features which add rigour to the research and draws upon the evidence from the literature to support the research design (Chenail et al. 2010).

To address the study question and account for the range and variety of data, this qualitative study took a pragmatic approach that integrated primary data in the form of semi-structured interviews with secondary data from the LIMBIC project. Qualitative, quantitative and mixed methods approaches have been taken towards undertaking research about service user involvement without any one approach standing out as the right way or the only way (Greenhalgh 2011; Paterson 2003). A variety of methodologies and methods have been used including case studies, evaluation studies, grounded theory as well as action research approaches such as participatory action research. Previous studies have also used different types of methods and methods mixes (Cresswell 2014; Armstrong 2013; Kreis 2012; Renedo and Marstin 2011; Attree et al. 2010; Gutteridge and Dobbins 2010; Wyatt 2008; Pickard et al. 2002). It was important for this current study to use an approach that kept a fit with the research question and Patton's (2002) framework was used to guide this research design.

The research design incorporated three inter-related stages. Stage One of the study consisted of an evaluation of the documentation associated with the LIMBIC project which informed the design of the LIMBIC project. It comprised documentation associated with the funding award and the LIMBIC research project proposal. The aim of this first stage of the study was to clarify the intended aim of involving service users in the LIMBIC project. Stage Two of the study comprised both primary and secondary data. The primary data came from semi-structured interviews with the patient representatives and the secondary data consisted of a range of different types of material from the LIMBIC project which related specifically to each of the patient representatives. In this stage a specific group of data was gathered for each

patient representative. Stage Three of the study consisted of data that related to the LIMBIC project but which were not specific to each patient representative. These data were from sources such as LIMBIC workshops, conferences, group meetings and events and the project wiki.

The dissemination strategy took account of the intended audience for the research findings (Patton 2002). In addition to the examiners of this thesis, this includes patients and potential patients or service users who may consider engaging in research, education, evaluation or service delivery initiatives. Findings would also be reported to academic scholars, health educators, health care professionals and managers who champion patient involvement, the funding body of the LIMBIC project (the Health Foundation), the host organisation of the LIMBIC project (Bournemouth University) and its collaborating organisations, the research team and the project participants including practice teams and patient representatives. Other organisations that would be informed of the findings of this study would include third sector organisations with a service user focus, Healthwatch organisations and local and national organisations promoting health service improvement, for example INVOLVE and the Patients Association. Processes for dissemination of the findings would include conference and poster presentations, publications in academic journals, articles in the lay press and social media approaches.

The LIMBIC project was undertaken between March 2007 and October 2010 and the current study between March 2008 and December 2012. The current study therefore commenced during the undertaking of the LIMBIC project and was completed after it had drawn to a close.

3.1   Philosophical perspective

As a health care professional, I hold an inherent belief that it is more than just a duty to provide the optimum experience for people who access health services for their care and treatment. Over many years I have supported the opinion that health care professionals and the teams to which they belong are in a privileged place and should use their skills and expertise to serve the people who seek care and treatment from them with honour, dignity and respect.

It is important for me, as the researcher for this study, to declare my prior knowledge in the field as part of the reflexive process in qualitative research (Malterud 2001). As a former health care professional (radiography), health service manager (primary care development) and latterly a researcher I have endeavoured in my roles to effectively involve service users in health service planning, delivery and evaluation and have been led to develop an inquiring mind about the process of service user involvement. I have a passionate attitude towards ensuring that the people who are dedicated enough to offer their time for involvement should be respected for doing so. I have made many contacts with devoted individuals who have given endless amounts of their time, effort, energy, expertise and enthusiasm towards believing in a system that engages with users of its services in order to improve those services for future users. See Figure 3.

Researcher's reflection

I thought back at this time to a moment about which I often reflect. In the mid 1990s, I was in the post of clinical governance co-ordinator for primary care working for a Health Authority in London. My role involved networking with other health care organisations about clinical governance issues and seeking opportunities for cross collaboration. This included attending monthly clinical governance committee meetings in several different hospital and community trusts in order to learn about each other's work and develop collaborative working.

On one occasion, Dr Marcia Kelson from the College of Health was an invited speaker at a committee meeting I attended. She talked of her work in service user involvement and gave many suggestions about the ways in which service user involvement could be implemented in health care. The passion with which she spoke and the sense it all made to me, inspired me with enthusiasm to be more pro-active in developing our own service user involvement work with general practice teams. This was when I began to work closely with service users and to convince others about its value to our health service.

Researcher's reflection, March 2008

Figure 3. Researcher's reflection 1

In 2007 a career move from the field of health service management and its corporate principles led me into the academic world to take on a role managing a health care research project. This project aimed to evaluate an educational initiative

in primary health care; the Learning to Improve the Management of Back Pain in the Community (LIMBIC) project. Focussed on the principles of quality improvement and giving patients as service users a central role in the research, this new piece of work led me to develop a research question that promised to give added insight and allow the exploration of the experience of being involved from the perspective of those who participate in research with primary health care teams.

I have outlined my position in relation to my employment role and my research role in relation to this study and I will now outline my epistemological stance, described here at the time I began to plan this research study, and drawing upon the unfamiliar language of the expert researchers (Figure 4).

Epistemological stance

To begin my research journey, it is important for me to be clear about the way in which I look at the world and make sense of it. I need to describe how I know what I know. As I approach my research I am reminded that I am seeing the world from a constructionist epistemological stance. I place emphasis on understanding and appreciating context, and that human beings construct meaning rather than receive meaning through definition by others.

The constructionist epistemology leads me to understand that I will need to have a patient-centred inquiry and to value patients' own interpretations of events. I will be constantly trying to place myself as near to the research participant as I possibly can so that when I interpret the findings they are as close as possible to the way in which the research participants would describe them.

As a qualitative researcher I will use a range of tools and methods in order to interpret the data. Each approach will make the subject visible in a different way and so I will find it helpful to use more than one tool or method of research practice.

My research style will be to work within and between competing and overlapping perspectives and paradigms. I am committed to the naturalistic perspective and the interpretive understanding of human experience.

Researcher's reflection, January 2009

Figure 4. Researcher's reflection 2

In clarifying my philosophical approach, I was drawn to the work of the American philosophers of the late nineteenth and early twentieth centuries and in particular

that of John Dewey (1859-1952). Preceding the work of Dewey, Charles Sanders Peirce and William James had developed pragmatism as a philosophical approach in their attempts to explain and improve the methods by which human beings acquired new knowledge and understanding of their environment, in the context of life in general, as well as scientifically. They clarified the concepts of meaning and truth, Peirce describing truth as reality - a way understanding a concept and so important in relation to scientific method while James took the pluralist view that there are different kinds of truths (Hookway 2010).

These early American pragmatists saw science as a dynamic activity, describing it as the process of finding things out, and using the term 'inquiry' to better illustrate its characteristics. Dewey described knowledge as one of the most important survival mechanisms we have and believed that our acquisition of knowledge was vitally important to us. In pragmatic philosophy, knowledge is defined as a social activity and the criteria of meaning and truth are related to this activity (Magee 1987).

The application of pragmatism in undertaking inquiry was about using methods that work out to be the most effective in the circumstances. As an approach to research where the outcomes are the focus of the inquiry, when it comes to decisions about methods, one of the major criticisms of pragmatism has been that it is essentially uncritical exploration (Crotty 2003). Using pragmatism to explore the meaning of experiences or culture, as Dewey later acknowledged, is about having an optimistic approach to inquiry and using methods and tools that work in a particular context.

Unlike other research paradigms, pragmatism does not have a unique set of principles for approaching the research. There are many differences in opinion about how it should be used to address the research question and many different ways which have been tried. Rorty (1989 in Powell 2001) described pragmatic theory as one which has the capacity to solve human problems.

Pragmatism is suited to this study as it allows the researcher to focus on the research problem instead of the methods (Cresswell 2014). My philosophical assumptions were therefore supported by my taking a pragmatic approach towards this research. With methods taking less of a priority the researcher has the freedom to use methods which are most suited to the research problem and emphasis is placed upon choosing explanations that lead to the desired outcomes. Pragmatism

allows the researcher not to have to make a forced choice about methods, logic and epistemology for the research.

Pragmatism is often used as the philosophical underpinning for mixed methods studies, that is studies using both qualitative and quantitative methods (Teddlie and Tashakkori 2009) and pragmatic researchers are often referred to as mixed methods researchers. It is also sometimes the case that a researcher taking a pragmatic approach to their study using a pragmatist worldview, focussing on the problem and not necessarily the method, will use one methodological approach such as qualitative approach and a mix of types of data, methods of data collection and data analysis.

Some researchers believe pragmatism to be anti-philosophy (Robson 2011) whilst others have described it as a crude philosophy because it allows for any set of ideas or theory to be 'true' but the important features of pragmatism is that it links belief, meaning, action and inquiry according to its early philosophers James, Peirce and Dewey. Inquiry for all pragmatists is a special way of acting and testing by action (Magee 1994).

The work of Habermas later supported the approach taken by the pragmatists. Habermas (2006) described how the political sphere needed input from citizens to give voice to society's problems. In his theory of communicative action, Habermas (1998) described the knowledge of society, culture and human relations as one which was generated through language and mutual understanding. People's actions arise in normal unself-conscious ways from people's deeply internalised and widely shared beliefs about their proper role in society (Bolton 2005). He believed that when knowledge was acquired through self-reflection that it led to empowerment and so through emancipatory knowledge it was possible to forget assumptions and think critically and differently which provided the opportunity of finding out new things and changing things. I drew upon the work of Habermas' (1984) suggestions of creating settings where the people come together and share their knowledge with partners in an atmosphere of mutual respect, equality and shared goals (Frankham 2009; Abelson 2003). This current study was therefore to be supported by the philosophical assumptions described as pragmatism.

3.2 Theoretical Framework

Using a theoretical framework provides a way of understanding the concepts that relate to a study and how they interact with each other. In this study the theoretical framework links the components which make up service user involvement in a way that gives a broader explanation of service user involvement in the context of this study. A suitable theoretical framework was required to help design and undertake the study which would best seek to answer the research question (Reeves and Hean 2013; Anfara and Mertz 2006; Denzin and Lincoln 2003a; Abelson et al. 2003). Searching for a theoretical framework to fit with research about peoples' experiences, I was drawn initially to the work of Edwards and Titchen (2003) who emphasised the importance of spending time evaluating the potential contribution of different theoretical perspectives in addressing the research questions in order to get a close fit between them. They argue that for much of the published research, the limitations that are described come as a result of inappropriate matching of inquiry purpose and theoretical perspective.

I have drawn upon Kerlinger's (1986 cited Anfara and Mertz 2006, pxiv) definition of theory as "a set of interrelated constructs, definitions and propositions" that provide a way of looking at a phenomenon by looking at the variables around that phenomenon and therefore lead to an approach towards explaining the phenomenon. The use of a theoretical framework for this study allowed me to present a number of concepts, constructs and propositions in such a way that they could be understood by others. I applied the theory to explain the broad approach to the study, its rationale and purpose and to predict outcomes for the study.

The theoretical framework along with the philosophical framework also allowed the linking of theory to the methodology and for this study this is adapted, with permission, from Morrow et al. (2012, p31). The framework takes account of contextual factors, methods of involvement, the involvement role and the outcomes (Figure 5). This adaptation of Morrow's (2012) framework fits with the patient representatives in their role in the LIMBIC project as well as in their role in this research. Distinguishing this study from the LIMBIC project is neither possible nor relevant for creating this theoretical framework.
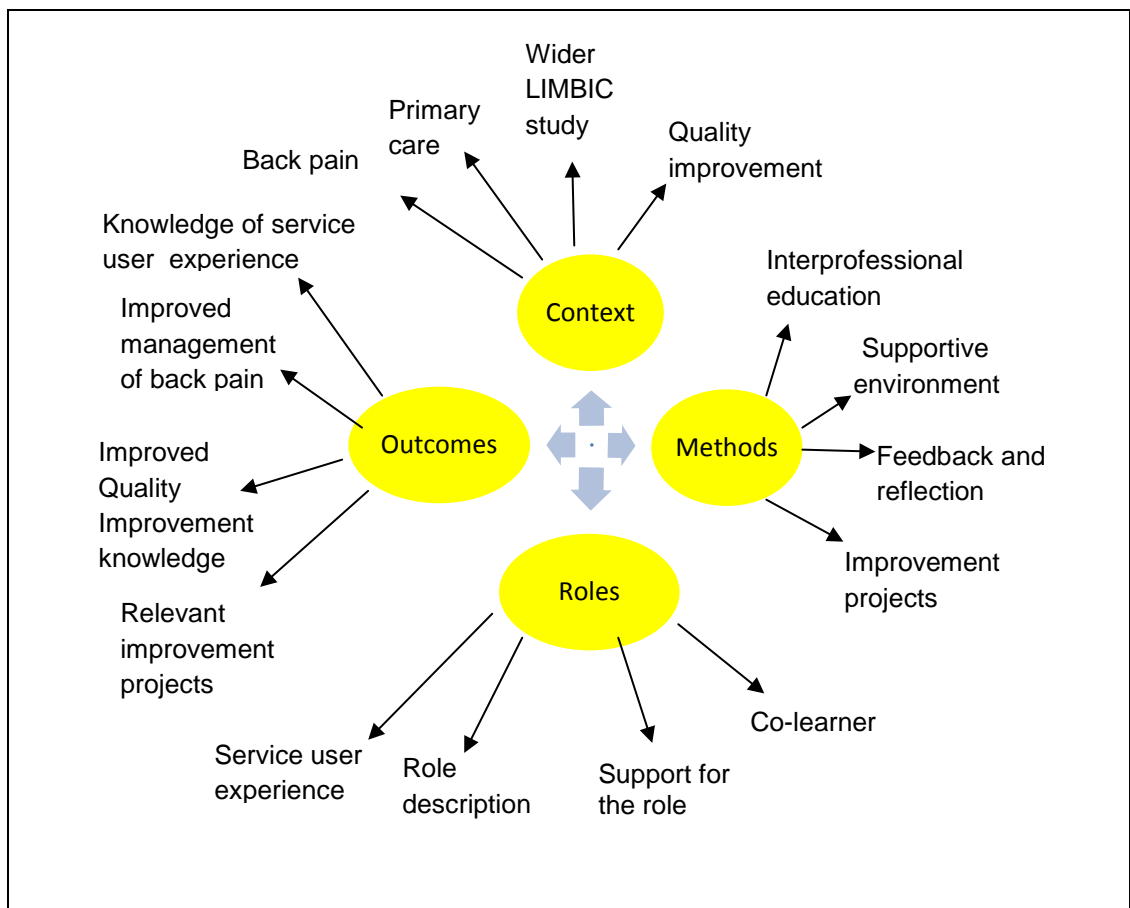
Figure 5. Theoretical framework for service user involvement used in this study - adapted with permission from Morrow et al. (2012)

Context

The context includes the background to the introduction of service user involvement in health settings and research, the different approaches to user involvement, the ethical issues and the issues specific to this study. These are around the principles supporting the management of back pain, and principles of quality improvement, the issues relevant to the primary care setting and the study being undertaken within the context of a wider research study, the LIMBIC project.

Methods

Methods are about the ways in which service users are engaged and the methods used by others in engaging with service users. This study explored the concept of learning together which was part of the interprofessional approach of the educational aspect of the LIMBIC project. This approach included a supportive learning environment where different types of support were offered and where

mechanisms for reflection and feedback were built in. The service users had engaged in improvement projects with the practice teams which placed them alongside the health care professionals.

Roles

Working alongside the health care professionals the service users in this study were co-learners and co-constructors. They were well supported with information, peer support and role descriptions to empower them in their other expert advisor role.

Outcomes

Outcomes that were anticipated through using this theoretical framework for this study were; that the improvement projects undertaken by the service users would be relevant to patients as well as to the practice teams, that all the learners would come away with improved knowledge of the principles of quality improvement, that practitioners would be managing back pain better, and that there would be new knowledge about the experience of service user involvement from the service user perspective.

Combining these concepts and applying them as an approach to understanding service user involvement in research, created a strong theoretical underpinning for the study to help focus the methodological approach and future understanding of the research process.

Application of this theoretical framework will be followed through the research design towards the collection and analysis of the data and eventually to the interpretation of the study findings (Denzin and Lincoln 2003b).

3.3   Ethical implications

The ethical considerations that were necessary at the start of this research were around gaining access to the participants, using the principles of autonomy around providing information and gaining consent, ensuring their safety and well-being, the confidentiality of the data they would provide and ensuring their anonymity. Gaining access meant gaining access to the participants of a study which had received formal ethical approval through the National Health Service Research Ethics

Service in July 2007. Ethical approval for this new study was obtained in two discrete processes, to account for both the inclusion of both primary data and secondary data extracted from the earlier LIMBIC project.

3.3.1 NHS ethics approval

In developing the research question, it became clear that it would be necessary to look at the detail of some of the data related to the LIMBIC project about the engagement of patient representatives. These data included reports of patient experiences, summary reports of patient representatives' pre-workshop support sessions, patient stories made available at the workshops and subsequently posted on the LIMBIC project wiki (an online information support tool – see Glossary) and other reports and summaries of contacts, events and communications. I therefore sought permission from the Co-Principal Investigators of the LIMBIC project to explore the data from the LIMBIC project for this doctoral research.

For the LIMBIC project, approval had already been granted for gaining access to the patient representatives to participate in focus groups with their practice teams both before and after the LIMBIC workshops, and to participate in the LIMBIC workshops and practice improvement work.

I therefore approached the NHS Research Ethics Committee which had given their approval for the LIMBIC project to seek their advice on using these data from the LIMBIC project for a purpose other than that which had been approved and as stated in the LIMBIC project protocol. I was invited by the Committee to apply for a substantial amendment to protocol and at their meeting on 10 October 2008 the Research Ethics Committee subsequently gave approval for an amendment to protocol (AM02) to allow me to use these data to inform my own research study design (Appendix 4). Exploration of these data led to the decision that research interviews with the patient representatives might be an appropriate method to use in order to explore their experience (Crabtree and Miller 1999).

I applied to the same Ethics Committee for a further amendment to seek approval to undertake interviews with the patient representatives from the LIMBIC project. This amendment (AM03) was approved in November 2008 (Appendix 4). A letter of invitation, a patient information sheet and a consent form were approved as part of

this process (Appendix 5). Therefore research ethics committee approval for this study was achieved through two amendments to the LIMBIC project proposal.

3.3.2   Other ethical considerations

Adherence to the NHS Research Governance Framework was required which I demonstrated in the study proposal and ethics application (Dixon-Woods and Yeung 2010). As a doctoral research project this study required approval through the processes of the University School of Health and Social Care Research Committee and Ethics Committee which was granted following the NHS ethics approval processes.

Through the formal NHS Research Ethics approval processes, the areas of informed consent and provision of adequate information about the study were addressed. The information sheet for the study (Appendix 5) explained the purpose of the study and what the participant could expect from engaging in the study as well as risks and benefits and the procedure for complaining as well as assurance of confidentiality. The funding source of the original (LIMBIC) study was also declared.

Management of risks around psychological safety were outlined in the NHS ethics application and included provision of access to a member of the LIMBIC project steering group or a partner organisation's helpline if this became necessary.

Providing anonymity ensures the identity of research participants can never be determined from the research material (Pitts and Smith 2007). To assure anonymity of the participants each of them was allocated a study code which was used throughout the research process and which was known only to me. Identification of individuals through study codes was not possible. Pseudonyms replaced the study codes at the point of writing up the findings of the data analysis adding further assurance that all data had been anonymised.

Confidentiality concerns the restriction of access to research material (Pitts and Smith 2007). Participants were assured confidentiality of their personal information and in relation to the data for this research through the consent process. I maintained a constant awareness that reporting of actions, processes, or narrative did not allow identification of individual participant.

There were occasions when reporting the findings of this research where it might have become possible to reveal the identity of a patient representative by the nature of what was being reported, for example, where only one patient representative had engaged in a particular activity such as a specific conference presentation or the production of a film. Pseudonyms have been withdrawn in these situations and the particular event or narrative has been reported without identifying the source in order to preserve anonymity. I have also anonymised further data related to a specific patient representative even though the data itself does not allow them to be identified. For example, the identity of some of the patient representatives is in the public domain because they feature in a film on a website or their name appears in a paper or article. If I had cited these examples in this study by giving their pseudonyms, the remainder of their data would no longer be anonymised.

Due to the nature of reporting research and the increasing use of social media, the fact that some of the patient representatives data from this study is in the public domain has provided me with an additional dimension to address with regard to maintaining confidentiality but I believe I have maintained rigour around this very important research domain.

3.4   Research quality and trustworthiness

It was necessary to clarify the processes used for ensuring rigour, trustworthiness and integrity of the research. In the context of this study, the trustworthiness indicated the extent to which the findings of the research could be applied across a wider population (Lincoln and Guba 1985). I maintained credibility by ensuring that the participants of the research recognised the research findings I presented to them and I used member checking, triangulation and openness about researcher bias to improve credibility.

Researcher bias

Prior to developing this study, I was already familiar to the patient representatives through my role as researcher and project manager for the LIMBIC project. It was during my experience of being involved in this way that I developed the idea for this research. The research participants were people who formed teams in general practice and patient representatives from their practice population. I worked closely with the practice teams in helping them to understand the purpose of involving

patient representatives in their project work and in recruiting them to the practice teams. I offered advice and support based upon my previous experience of working with service users in service development, evaluation and improvement initiatives. I believe that my position in relation to the service user participants provided the opportunity for the development of mutual trust between myself and each of the participants which might have influenced the way in which I undertook the research interviews and subsequent analysis. Through a reflexive approach, I tried to maintain a constant awareness of this potential for bias throughout my engagement in the study and when undertaking the analysis. I also needed to acknowledge that this familiarity might have influenced their decision to take part in an interview, or not. It might have influenced what they chose to say in the interview setting, or what not to say.

In my role as project manager, I took opportunities to gain an improved understanding of the role of the patient representatives and to understand their opinions about what was being asked of them. Through my attendance at each of the LIMBIC workshops, by undertaking each of the pre and post workshop focus groups and through close liaison with the LIMBIC quality improvement facilitator, I gained proximity to patient representatives who later became the participants for this research study. I engaged with them in their facilitated learning sessions on the morning of each LIMBIC workshop, and as a result of this I gained insight into each of their backgrounds and experiences. I believe that I had developed a relationship of trust.

I was aware at the time of the workshops, however, that I would be exploring some aspect of the patient representative experience and so would have been unconsciously observing the patient representatives, perhaps making mental notes which I thought were relevant and engaging proactively because I knew I would probably wish to gain in-depth information from the patient representatives in the future for this further research. I have maintained awareness in writing up my findings about what has resulted directly from this research and not from my prior knowledge or assumptions. My prior involvement with the patient representatives of this study meant I had insider knowledge of their involvement in the LIMBIC project and of the events that occurred. I came to know the patient representatives and this might have made it easier for them to be open with me in their interviews.

When approaching the data collection, data analysis and interpretation of the findings of this study, I tried to set aside my assumptions from these observations. I was aware of the distortions through my being known to the participants and having developed a working relationship with them. I had made personal observations about the group dynamics between the service user participants and made assumptions about their relationships between and attitudes towards one another. I found it useful to deal with this through reflection and noting in my reflexive account. I made notes about things which surprised me about the experience of being with the service user participants, some of these things were comments and some were things that people did.

Triangulation

The process of triangulation of research material has been described in different ways by different researchers (Flick 2009). In a very general sense, triangulation is the verification of one set of information by seeking an alternative source and finding the same set of information. The pragmatic approach taken towards this research made triangulation possible and I was able to use and compare different sources of data, different methods of data collection and different approaches to data analysis. I used triangulation of data by matching different types of data from the same source, for example, when I analysed the patient representative specific data I used a template for each participant's group of data which took a stepped approach to looking for verification, contradiction and new meaning, for each patient representative. I was able to view the sources of data alongside each other to verify the assumptions I was making about my findings.

For each patient representative I gathered data from stories, emails, phone conversations, focus groups, interviews and the wiki. By using a variety of methodological combinations to explore the research question, combining different analysis processes and through triangulation I have attempted to amplify the trustworthiness of this research study (Tracy 2010). These processes are detailed later in this thesis in the description of the data analysis for each stage of the study in Section 3.5.

Member checking

I invited patient representatives to comment on the transcript of their interview to give them the opportunity to retract any material or suggest alternatives in the case

of any ambiguity, as well as to confirm the accuracy of their interview transcripts. All patient representatives agreed their transcript was an accurate record of the interview they had given and other observations they made were about the length of the document and their observations about seeing their dialogue in written form, for example "Do I really talk like that?" (Patient representative LIMPR04).

Transferability

In order to enhance the potential for these research findings to be transferred to similar situations or participants, I have given accurate and detailed descriptions of every aspect of this research study so that those reading the research account can have a clear understanding of the whole process. As a qualitative researcher, I am committed to providing the widest possible range of information in the description of this research. I believe I have provided depth of detail about the background, the planning and the processes involved in undertaking this research that is sufficient to allow others to make judgements about its potential for transferability.

Dependability

I have maintained meticulous records of the research processes at all levels therefore illustrating the dependability and confirmability of this study. For example I have illustrated my record-keeping processes by providing screenshots in this thesis of my computer filing systems for the study data. See Section 3.5.

Confirmability

In order to be able to illustrate that the study findings are the result of the research and are not due to researcher bias, I have used reflexivity to enhance confirmability. In order to be confident that a confirmability audit could take place, I have systematically documented all the study data including the study code, description, the data source, the type of data, the purpose in relation to this research and the proposed method of data analysis for each item of data. I have used a consistent approach for managing all of the groups of data that I have identified as relevant for the research in relation to the potential contribution to the research question. I have documented the stages of analysis for each set of data in the data analysis strategy. Where I have extracted data or reduced the data from the original documentation, I have documented this. I have recorded my initial thoughts and themes for analysis in my research audit record as well as in the initial documentation. I have matched

voice files to transcripts for interview data and saved these records in the research files ensuring that I maintained the anonymity of the participants.

Reflexivity

Keeping a record of my thoughts about myself and what I have perceived to be my influences on the research process and data at all stages of the journey has been an important and relevant aspect of the whole research. I considered who the research was for, what it was for and how my values would influence the research to increase the chances that the research study would mirror reality (Mayan 2009). I have declared my position in relation to my training, preparation, access to existing data, collection of new data and data analysis processes and in relation to those data associated with the LIMBIC project. I have acknowledged that the judgements I have made in relation to the significance of the research findings are influenced by my own personal perspective, background, awareness and consciousness. My main assumptions included, for example, the way I viewed things as a former clinician, and as a person with experience of working with practitioners in the primary care environment. At each stage, I reminded myself of these assumptions in order to ensure that I maintained an awareness of these examples to endeavour to minimise the influence of my assumptions on the research processes.

Some of the prior knowledge I held in relation to the LIMBIC project was difficult to set aside when working with the patient representatives during their interviews. This may have influenced the data analysis processes and research findings. During this time I tried to separate my dual roles. I retained the LIMBIC project manager role in relation to working with the patient representatives and made a conscious decision to withhold from engaging in the analysis of the patient representatives interviews' until after my role as project manager for the LIMBIC project was over some two years after I had collected the data.

By exhibiting transparency in my approach towards all aspects of the design, undertaking and reporting of this research I believe I have demonstrated its trustworthiness so that others can realise the processes I used and make their judgements about the credibility of the findings.

Researcher credentials

Reporting of researcher credentials in research about service user involvement is recognised as adding to the evidence base of well reported studies (Mockford et al. 2012). This study was led by me as postgraduate researcher and doctoral student and supported by four academic supervisors with expertise in qualitative research, pain and service user involvement. Their clinical backgrounds were in nursing (Supervisors 2, 3 and 4) and pharmacy (Supervisor 1). Supervisor 1 supported me in my doctoral studies throughout and after leaving the academic institution to work abroad in 2010. Supervisor 2 also supported me throughout my doctoral studies and exchanged roles with Supervisor 1 to become first supervisor in 2010. Supervisor 3 supported me until leaving the academic institution to work abroad in 2011. Supervisor 3 was a co-principal investigator of the LIMBIC project. Supervisor 4 replaced Supervisor 3 who departed in 2011. Supervisor 4 moved to another academic institution in 2012 but retained the role of supervisor for my research. See Table 2. All supervisors had experience of doctoral supervision to completion and extensive publication histories.

Researcher	Academic and professional qualifications
Supervisor 1	BPharm, PhD, MPSNZ, AMRCM
Supervisor 2	BSc, PG Dip, MPhil, PhD, RGN
Supervisor 3	BSc, PG Dip, MSc, PhD, RN
Supervisor 4	BSc, PhD, RN
Doctoral researcher	MSc, PGCert Ed, DCR, DMU, HDCR

Table 2. Researcher academic and professional qualifications

Undertaken within a UK based academic institution, the research team for this study was supported by organisational frameworks and guidance on core research activities as well as nationally recognised frameworks and guidance. These included; the Economic and Social Research Council (ESRC) Framework for Research Ethics, the National Health Service Research Ethics Service, the Vitae Researcher Development Framework, Research Professional, the Researcher Concordat, Research Excellence Framework, Bournemouth University Health and Safety Policy and Bournemouth University Research Governance Framework.

Researcher support and development

Researcher training was part of an on-going process of being a postgraduate researcher and, by attending the Bournemouth University Graduate School Programme for Postgraduate Researchers, I became equipped with the knowledge and the tools that were considered necessary in order to be prepared to undertake this study. During the course of my engagement in the LIMBIC project and in this study I have been supported academically and have taken up a number of training opportunities made available to me which have enhanced my credibility as a researcher and my confidence in the quality and trustworthiness of my work. See Appendix 6.

3.5   Methodology and methods

This study was undertaken at a time when there was no substantial body of evidence to support any one particular methodology for research about service user involvement. There was an abundance of methods and methodological approaches to choose from, each with their own rationale for use alongside their restrictions and limitations. A philosophical and methodological approach was chosen that allowed for the data to lead the direction of the study coming from the real world of human experience at that time.

In deciding upon an appropriate methodological approach I was aware that the intended study would need to take an approach that placed emphasis on understanding how people experience and interpret their situation and as such would need to take a qualitative approach. The research would produce knowledge that emphasised words and meaning through its collection and analysis of data. I would use the LIMBIC project as a vehicle for getting my data, in this context use the LIMBIC project as a case study to explore the principles I had set up to achieve my study objectives. I considered the merits and appropriateness of the main qualitative approaches.

Phenomenology

Phenomenology would have permitted the interpretation of the meaning of the lived experience of the research participants through their own description (Gerrish and Lacey 2000). The accounts of patient representatives' experiences would have

permitted interpretation of their experience of being engaged in the LIMBIC project. I also understood that a very small sample would have allowed sufficient in-depth engagement with each individual case but the requirement to undertake very in depth analysis of this small number of cases might have limited my study in terms of the wider objectives which included a wide range of data from different sources to be analysed (Smith and Osborn 2003). Phenomenological sociology which has been used for research into patients' perspective (Edwards and Titchen 2003) or an interpretive phenomenological approach (IPA) (Smith and Osborn 2003) which explores people's lived experience might also have been possible if I had chosen to limit my study to the participants experience without drawing upon the data from the wider LIMBIC project.

Action research

I considered action research as a possible approach as it would have allowed me flexibility in the approach or intervention I might choose. As the researcher I would have been able to change the format or the intervention for the research. However, as this study was so closely interlinked with the LIMBIC project I felt that I would have been limited in my capacity to alter the intervention. Action research, or participatory action research where the participants or practitioners are involved in the change, focuses more upon the capacity for the researcher to introduce change which was not a goal of the study (Koshy 2005). To an extent the LIMBIC project itself used a form of participatory action research where practitioners made small changes in practice, but this current study intended to explore the LIMBIC project more broadly as well as explore the participants' experiences in depth.

Narrative research

The study was likely to use some form of narrative materials, analysing data that had been collected as stories, but this would not be the overall approach to the study. Narrative research describes and captures meanings at the individual level about their life events. Hoever, for the participants in this study the focus was on their experience of their journey through a research study and involved the use of secondary data from that study as well as their own accounts and therefore the analysis of narrative data alone was not the aim of the study.

Emancipatory research

This approach would have involved the participants in actually undertaking the research (Beresford and Wallcraft 1997) and whilst this might have been an appropriate approach to consider, I was mindful that I did not want to alter the role of the LIMBIC project participants that might affect the findings of that study so I did not consider this approach to have been suitable.

Ethnography

In a sense the participants of the LIMBIC project could be described as a specific subculture and therefore potentially be explored through an ethnographic approach. The behaviour of the individuals within that subculture was not however the particular focus of the study. I would not be expecting to describe a cultural phenomenon through abstract patterns and traits of the life within a particular culture. There might have been some aspects of ethnography that I could use in the study such as observation and interviewing, letters and documents of the people in the particular group in the study. Frankham et al. (2009) recommended ethnography for partnership research but the nature of the current study was not focussed specifically on partnership research.

Grounded theory

I did not consider grounded theory as an appropriate research approach even though it is considered suitable for the observed behaviour of people in particular situations. The area of service user involvement had been explored before and the gaps in the literature were known so the development of new theory in this particular setting did not feel appropriate.

Choice of approach

In taking a flexible approach to the topic and the methods at the start of the study I wanted to be able to refine the research and steer the progression of the study towards answering questions that were uncovered during the process in the light of new information gained (Smith et al. 2005). I recognised the different paradigms with different approaches and designs and different ways of making meaning and different ways of knowing (Cook 2012). I knew that I would probably need to use different forms of analysis for the different sets of data. As I recognised that I needed to use multi-analysis I began to consider the mixed method pragmatic paradigm.

There are contradictions in the pragmatic approach; many criticise the approach describing it as a 'pick and mix' approach indicating that it is not considered a traditional research paradigm. However I would argue that the pragmatic approach gave this study a breadth of data sources and depth of data for analysis that was able to yield insight across the broad range of the participants' engagement. This permitted depth of exploration of their experiences.

In searching for a methodological approach to fit with this research I also considered phenomenological sociology (Edwards and Tichen 2003), action research (Cohen at al. 2007) and emancipatory research approaches (Williamson 2010) but none of these really illustrated a close fit with this study after further exploration due to the nature of the setting for this study and the conditions which were already in place for the wider evaluation study (LIMBIC). Whilst phenomenological sociology would have been a useful approach to underpin research into the interpretation of others, it did not fit with the research question I was asking, about exploring the experience of others. It focussed more specifically on how others develop their assumptions and opinions. I therefore rejected this as a methodological approach for my study but considered it possible that I might use some aspects of it if relevant. There were aspects of action research which seemed to fit with the approach I intended to use. However, the evaluation of the LIMBIC project was underway and as the role of the patient representatives was already defined, I felt the scope for influencing their actions was not relevant but I considered that I might prefer to draw on some of the principles of action research such as those around empowerment. I also considered the use of emancipatory research but this did not seem relevant as the research did not intend to focus on patients being in control of the research, at that time.

I explored examples of methodological frameworks which had been used for service user involvement studies. These included those reported by Brett et al. (2010); Oliver et al. (2008); Smith et al. (2006); the Australian Government National Health and Medical Research Council (2004) and Forrest et al. (2000).

Brett et al. (2010) reported on the PIRICOM study, a systematic review of the conceptualisation, measurement, impact and outcomes of patients and public involvement in health and social care research. Their review identified several frameworks which had been developed for use in studies involving patient and

public involvement. Brett at al. (2010) reported the work of Oliver et al. (2008) which suggested an eight dimensional framework mapping the degree of public engagement with the researcher's degree of engagement with the public. This framework did not fit with this current study as its use was for public involvement in setting the research agenda.

The PIRICOM study also reported the work of Pivik et al. (2003 cited by Brett et al. 2010) which assessed two further models; a Breast Cancer Consumer Involvement Model from Australia (2004 cited by Brett et al. 2010) and a consumer involvement model from the UK National Institute for Clinical Excellence (1995 cited by Brett et al. 2010). Neither of these models was suitable for this current study because they represented the involvement of patients in contributing to the work of national bodies with responsibilities for delivering models of involvement that would work at a national level. Other frameworks reported by Brett at al. (2010) included Telford et al. (2005) who described eight principles and indicators for successful patient involvement, Abelson (2007) a framework for involvement in Health Technology Assessment Research in Canada, McCormick (2004) a framework for involvement in breast cancer research, and Dewar (2005) a framework for criteria to support older people in patient and public involvement. Brett at al. (2010) acknowledged that the frameworks they reviewed identified factors that could be linked to context and process factors of patient and public involvement, but were not developed sufficiently to provide the theoretical modelling that was required in order to be able to conceptualise patient and public involvement.

I did not find a suitable match of qualitative methodological framework for this research question and was drawn to considering that of pragmatism as it allowed more focus on the problem to be researched and the consequences of the research (Feilzer 2010). Using pragmatism permitted the use of different research methods as well as modes of analysis and was guided by the research goal of producing socially useful knowledge without restricting the research to the use of one type of approach (Johnson and Onwuegbuzie 2004).

This study therefore used a qualitative approach of naturalistic inquiry in order to gain insight into the experience of participants in an interprofessional education evaluation study. I was not forced to use one single method or mix of methods and I was not expecting to find causal links or truths. I explored the research question

with the most appropriate research method for each group of data. Using pragmatism gave me a commitment to uncertainty and the knowledge that was to come from the research would be relative and not absolute. The human element within the research process allowed me to be flexible and open to the collection of unexpected data. I saw it as my duty as a researcher to be curious and adaptable. I took a "needs-based, contingency approach" to the research study (Johnson and Onwuegbuzie 2004, p17).

Had I used one single approach for my research, this might have constrained my intellectual curiosity or my ability to embrace the presence of new phenomena - another reason for my attraction to the pragmatic approach. Pragmatism allowed me to put aside the issues of truth and reality and accept philosophically, that there are single and multiple realities that are open to inquiry (Feilzer 2010). I was able to solve problems in a practical way as they occurred. As a pragmatic thinker I believe that reality is very much based on what is useful to me and I accept as one possible reality the ideas that work for the data and my reading of it in a broad sense. Taking a pragmatic approach to this research meant that the decision-making processes were guided by my philosophical perspective and I therefore also anticipated findings which would hold congruence with that perspective (Teddlie and Tashakkori 2009).

Others have loosely described pragmatism as an 'anything goes' perspective (Seale et al. 2004, P5) but I would argue that by focussing on what is useful in practice the pragmatic researcher is not being unsystematic about methods or procedure but is implementing self-conscious and systematic methods for addressing the things that they research. Pragmatism starts by looking at the things that the social world is made up of, whereas some other qualitative approaches bypass the real world influence on the research (Seale et al. 2004).

I approached the evaluation of the data from the LIMBIC project based upon a case study type of approach (Flyvbjerg 2006). As Stake (2000) argues, all evaluation studies are case studies. This study was a case study in the sense that it was a concrete example in a specific setting, about patient participation in health research (Abma 2005). In this context the use of a case study was not a choice of methodology but a choice about what was being studied (Stake 2000). I organised the data in preparation for in-depth analysis and comparison. The case was the

LIMBIC project and this was the unit of analysis. The case study was the result of the analysis process. Data for the case came from the LIMBIC project and included focus group data, documentary data, film, a wiki and educational material. In the process of undertaking the case study I brought together and organised all of the LIMBIC project data into one comprehensive package of data. I drew together a data analysis strategy (Appendix 7) to assist in the organisation and management of the various sources of data. This strategy provided an overview of the processes for the identification, collection, management and analysis of the data for the study.

Data saturation

The point of data saturation in a qualitative research study is when the collection of new data does not shed any further light on the issue under investigation and this is the point at which the sample size for the study is achieved (Mason 2010). It is suggested that it becomes obvious as the study progresses and as new categories or themes stop emerging from the data that data saturation has been reached (Marshall 1996).

The sample size for this study was determined by the number of consenting participants for the research interview and the data associated with their engagement in the study. In that sense there was a limit to the number of datasets that were available to analyse. The methods of analysis and the combinations and variations that were available for undertaking the overall analysis however, were potentially numerous.

In relation to data saturation, for pragmatism, as with grounded theory for example, it can be difficult in practice to decide when categories are saturated because some researchers argue that if the researcher continues to analyse the data there is always something new to be found (Strauss and Corbin 1990). Had I used a defined methodology such as phenomenology I could probably more clearly say at which point I had reached data saturation because I would probably have used one single method of data collection and one source of data, therefore leading to a smaller potential sample size for the study. Pragmatism uses different ways of data collection and different methods of data analysis. Through using multiple sources of data and therefore having the potential to continue taking a range of approaches towards the analysis of different combinations of datasets, the point of saturation by Mason's (2010) definition might never have been reached. In this study data

saturation was achieved when the themes arising from the analysis of the different levels of integrated data from the three stages of the study were no longer new themes. The data analysis was leading to themes that had already been identified.

Using secondary data limited the opportunity to achieve data saturation as there was a limit to the number of datasets available for analysis from the LIMBIC project. Although the key themes had developed and further themes were not being seen, it was not possible to arrive at the stage where I could be confident that no additional data could be found to develop further themes (Glaser and Strauss 1967). As Andrews et al. (2012) described in their undertaking of grounded theory using secondary data I took the decision that the data set was large enough for me to feel confident that data saturation had been reached.

The data collection and analysis for this study was undertaken in three stages which are illustrated in a sequence in Figure 6. Although the three stages did not occur in a linear pattern - the data were analysed concurrently - they are described sequentially for ease of understanding.

Stage Two: A
patient representative interviews

Stage Two: B
Other patient representative specific data

Stage Three
LIMBIC project specific data

- Call for Research Proposals
- Research proposal
- Evaluation of the funding scheme
- Supporting information for patients and practices

Stage One
LIMBIC project background data

- Semi-structured interviews with patient representatives formed the source of primary data
- Semi strucutred interview transcripts were analysed thematically and integrated with the data from other data from stage two

- Patient stories
- Interim review reports
- Practice team improvement projects
- Emails, phone calls, correspondence notes
- Wiki photo gallery
- LIMBIC film – A Day at the Races
- Filmed interview about user involvement for the Health Foundation

- Workshop presentations
- Workshop Fast feedback
- Wiki
- Patient representative pre-workshop meetings
- Workshop reflections
- Learning event
- LIMBIC illustration
- Celebratory and Dissemination event
- Conference posters and presentations
- Papers and publications
- Advising commissioners

Figure 6. Sequence of the stages of data collection and analysis

The data from Stage One of the study represented data related to the LIMBIC project prior to the commencement of the LIMBIC study and this stage was intended to provide insight into the purpose of involving service users in the LIMBIC project by exploring the documents associated with the funding award.

The data from Stage Two of the study related directly to the patient representatives of the LIMBIC project about their engagement in the project and this stage also included the semi structured interview data. This stage aimed to explore the perspectives of patient representatives about their experience of involvement.

Stage Three of the study reviewed data that supported the delivery of the LIMBIC project but was indirectly associated with the patient representatives' experiences. It included data that was more generally associated with the LIMBIC project and included the educational material associated with the workshops, dissemination events, reports and publications. Table 3 shows the sources of data and stages at which they were collected, grouped and analysed.

The group of data labelled D3.1 formed the primary data for this research – the semi structured interviews. The remainder of the data came from the LIMBIC project and secondary data analysis was used with a view to gaining an understanding of the context of the study in which the patient representatives were involved and their service user involvement role within it. The methods used for the data collection involved a retrospective data gathering exercise and a series of semi-structured research interviews (Marshall and Rossman 2006). For each group of data, the criteria which required identification before the analysis process were:
- data source
- type of data
- the purpose of using the data for this study
- the research objective for this study which was relevant for this data
- the method of analysis.

These criteria were used to create a template for presenting the data analysis summary for each group of data including the plans for analysis. This series of templates formed the document which later became the data analysis strategy (Appendix 7). For the secondary analysis I used a retrospective interpretation of the data from the original (LIMBIC) study to permit the consideration of new questions

that might not have been thoroughly examined in the original study (Thorne in Morse 1994).

Data code	Name of data source	Study Stage
D1.1	Call for Research Proposals (LIMBIC Project)	Stage One
D1.2	LIMBIC Project Research proposal	Stage One
D1.3	An evaluation of the Health Foundation's Engaging with Quality Initiative - Second Annual Report	Stage One
D1.4	Support information for patients and practices	Stage Three
D2.1.1	Patient stories	Stage Two
D2.1.2	Workshop material	Stage Three
D2.1.3	Workshop Fast feedback	Stage Three
D2.1.4	Transcripts of Focus Groups with practice teams	Stage Two
D2.1.5	Interim review reports	Stage Two
D2.1.6	Wiki	Stage Three
D2.1.7	Practice team improvement project work	Stage Two
D2.1.8	Patient representative pre-workshop meetings	Stage Three
D2.1.9	Emails, phone calls, correspondence notes	Stage Two
D2.1.10	Reflections on the Workshops	Stage Three
D2.1.11	LIMBIC photo gallery	Stage Two
D2.2.1	Learning event	Stage Three
D2.2.2	LIMBIC film – A Day at the Races	Stage Two
D2.2.3	LIMBIC illustration	Stage Three
D2.2.4	Filmed interview about the experience of user involvement in research made by Health Foundation	Stage Two
D2.2.5	Celebratory and Dissemination event 090909	Stage Three
D2.2.6	Conference posters and presentations	Stage Three
D2.2.7	Papers and publications	Stage Three
D2.2.8	Advising commissioners	Stage Three
D3.1	Semi structured interviews	Stage Two
D3.2	Other interview	Stage Two

Table 3. Data codes, sources and stages of analysis

For the text based documents in this analysis I took the pragmatic approach that not all of the text was going to be relevant to the research question and therefore meaningful data for this study. I would look for the interpretive elements in the text-based documents and adopt a critical awareness about what would count as data. For the semi structured interviews and the other qualitative research data a thematic analysis was used (Warren in Gubrium and Holstein 2002; Aronson 1994).

3.5.1   Stage One of the Study

The purpose of Stage One of the study was to explore the background and rationale for service user involvement in the LIMBIC study to ascertain the contribution made by the service users towards the design, process and outcomes of the LIMBIC study. The data for this stage of the study included the project documentation that related to the funding award made for the LIMBIC project.

3.5.1i   Stage One: Sample

The sample of data that related to the identification of the rationale for service user involvement in the LIMBIC project was defined as that which related to the pre-award status of the project, that is the project proposal and the guidance and application form from the funding body, the Health Foundation (Table 4).

D1.1	Call for Research Proposals (LIMBIC Project)	Stage One
D1.2	LIMBIC Project Research proposal	Stage One
D1.3	An evaluation of the Health Foundation's Engaging with Quality Initiative - Second Annual Report	Stage One

Table 4. Stage One of the study – Sample

3.5.1ii   Stage One: Data Collection

In my role as project manager and researcher for the LIMBIC project I had access to all the data associated with the project which were filed on a shared computer drive which was accessible only by the research team including myself. I saved a version of each of the documents, shown in Table 3 in my research computer files.
I set up folders on my computer to store these data ready for subsequent analysis as shown in Figure 7 and I allocated a study code to each one.

Figure 7. Screenshot of folder holding Stage One data

3.5.1iii Stage One: Data analysis

This study used multiple data sources and methods of analysis. Both content and thematic analyses were used. For much of the project documentation, content analysis was used to illuminate the features that were related to the experience of patient involvement. The data analysis strategy (Appendix 7) was used to guide the management and the analysis of the data. The data used in the analysis of Stage One of the study were:

D1.1 Call for Research Proposals

The documentation associated with the Health Foundation Engaging with Quality in Primary Care Scheme call for proposals consisted of several documents:
   a) Call for Outline Proposals
   b) Specification for Full Applications
   c) Guidance on completing the application form
   d) Guidance about the evaluation of the scheme
   e) Frequently asked questions

D1.2 LIMBIC Project Research proposal

This document contained the detail and supporting evidence for the proposed LIMBIC project.

D1.3 Evaluation of the Engaging with Quality Initiative

This document was a progress report of the evaluation of the Engaging with Quality award scheme which preceded the Engaging with Quality in Primary Care (EwQ primary care) award scheme. The EwQ scheme consisted of awards made to

healthcare professional bodies with the primary aim of engaging with clinicians in quality improvement initiatives.

Summary of Stage One

The documents associated with the initial design and planning of the LIMBIC project were analysed in Stage One of the study to clarify the aims of involving service users in the project so that it would be possible to determine whether these aims had been met.

3.5.2   Stage Two of the Study

The purpose of Stage Two of the study was to explore the experience of the patient representatives who were involved in the LIMBIC project. This involved undertaking the semi-structured interviews with patient representatives and thematically analysing the interview transcripts (Stage Two Group A, shown in Figure 6). Semi-structured interviews were chosen as they were expected to gain rich data for qualitative analysis and it was expected that some degree of systematisation would be required (Marshall and Rossman 2006; Seppanan-Jarvela 2004).This was followed by collecting data from the LIMBIC project that related to the patient representatives about the process of their involvement (Stage Two Group B, shown in Figure 6) and thematically analysing these grouped data for each patient representative. The process for undertaking semi-structured interviews is described first.

3.5.2i   Stage Two: Sample – Group A

The study sample for Stage Two of the study - Group A, for the research interviews was drawn from the cohort of LIMBIC patient representatives who were already involved in the LIMBIC project. The process used to recruit patient representatives to the practice teams for the LIMBIC project is therefore explained. This is followed by a description of the process of recruiting the sub-sample from these individuals to participate in a research interview for this current study.

The practice teams involved in the LIMBIC project were recruited by the LIMBIC research team by invitation from a cohort of 112 practices across three primary care trusts in the south of England. Invitations were made via email to the practice

manager and followed up by a phone call from the researcher. Nine practices were recruited, failing to meet the study target of ten practices. Before the LIMBIC workshops commenced, an information pack for patients and an information sheet for practice teams was made available to assist practice teams in their efforts to recruit a patient representative to their improvement team. The LIMBIC research team developed this guidance based upon that provided in the INVOLVE Patient Information Pack (INVOLVE 2006).

To assist them in their decisions about whether to agree to take on the role of patient representative, those considering the role were offered guidance as outlined in Figure 8. The role guidance also contained information about maintaining confidentiality around the conversations about planning improvements in each practice.

Entry criteria for patient representatives to the join practice teams for the LIMBIC project were adults who:

- had used the services of their GP surgery for one episode or more of back pain.
- were able to attend the eight monthly workshops which were held on Thursday afternoons over a nine month period in 2008 alternating across two sites in two counties.
- were able to attend the practice team improvement project meetings which were held during the working day and at separate times, in between the workshop sessions.
- were able to contribute to the practice team improvement projects by offering advice and guidance from their perspective.

Extract from Patient Representative Role Guidance

Patient representative members of the practice workshop groups, like all members of the group, are there because of their personal knowledge and experience. All members of the workshop group have equal status even though their areas of expertise may vary. No formal qualifications are needed, but it is important to have:

- experience of accessing healthcare with experience of back pain and of issues important to people with back pain.
- an understanding of, and a willingness to reflect, the experiences and needs of people with back pain.
- time and commitment to attend workshops and possibly attend meetings with the practice team in between the workshops.
- good communication and team working skills, including respect for other people's views, and the ability to listen and take part in constructive debate.
- the ability to maintain confidentiality as required.

A key role for patient representatives is to ensure that the views, experiences and interests of patients inform the group's work. This may include:

- identifying issues of concern to patients or carers to help develop key questions for the group to answer within the series of workshops.
- making sure that patients' perspectives are taken into account when the group decides upon a plan for improvement in practice.

Taking part in this type of work can raise personal issues for some people, for instance about their own experience of the condition, or about treatment that they are undergoing. Patients considering putting themselves forward should bear this in mind.

Patient representatives are offered a payment of £50 for attending each of the workshops. There will be an expectation that the patient representatives will attend meetings at the practice in between the workshops, to discuss the on-going improvement initiatives. All travel costs incurred will be reimbursed.

Patient representatives may use their specific experience and expertise by helping to identify patient-focused questions for improvements to practice and assessing whether the group's suggestions for improvements:

- address the treatments, interventions and outcomes that are important from the perspective of patients
- ensure patients' views and preferences are taken into account
- address the needs of relevant groups of patients, such as people from specific ethnic or cultural groups, or different age groups
- address patients' information, education and support needs in relation to back pain
- respect patients in wording and tone.

Figure 8. Extract from Patient Representative Role Guidance

The convenience sample of patient representatives provided by the LIMBIC project permitted inquiry into understanding the experience of the service users, from their perspectives, and to address the research question. At the time of designing the research study I considered undertaking a second round of interviews with the

patient representatives, to help validate or enhance the findings from the first round of analysis. I expected that if there was a need for validation through further interviews, this would emerge during the analysis stage.

3.5.2ii Stage Two: Data Collection - Group A

Following the formal receipt of ethics committee approval to undertake semi-structured interviews (Appendix 4), and following the outcome of the initial review process of my doctoral research programme, the LIMBIC patient representatives were invited for interview. The research interview was used to attempt to understand the experience of being involved in the research project from the patient representatives' point of view and to gain depth of detail about the meaning of their experiences (Warren in Gubrium and Holstein 2002; Kvale 1996). The plans for undertaking the research interviews with patient representatives were discussed in detail with my supervisory team and an interview guide (Figure 9) was developed to support the data collection process and to help overcome the challenge of keeping the interviews open-ended (Silverman 2010).

Interview Guide

Tell me about your experience with the project.

Describe your experience working with the research project.

Is there anything you would like to say about meeting other patients?

What was it like learning with practice teams?

What was it like working with research team members?

How did you find learning about improvement?

How did you find learning about back pain?

What would you like to see happen now?

Were your expectations met?

How did it make you feel? From your perspective, how has it been?

Version 5   23 March 2009

Figure 9. Interview Guide

Each of the eleven patient representatives was invited by letter in February 2009 to participate in a research interview. The information sheet, consent form and a reply-paid envelope were enclosed (Appendix 5). Their contact details were available to me through my role as project manager for the LIMBIC project. The interview date and time were agreed by telephone after an offer was made to answer their queries if they had any.

A research file for each patient representative was set up which recorded information about all contacts with each individual and each one was allocated a unique study code to ensure anonymity. The files were stored electronically with other research data which was password protected and hard copy versions of these data were held in securely stored files. The study codes allocated to each group of data for each patient representative were later replaced with pseudonyms and identities are known only to myself, but can be accessed through a password coded mechanism for quality assurance and audit purposes.

Interviews were recorded using an Olympus DSS digital voice recorder and with permission from the patient representatives to do so. Patient representatives were invited to speak about the aspects of their experience without the aim of gaining any particular response. A time limit was agreed in advance for each interview which was extended with permission if necessary. Participants were told they would receive a copy of the interview transcript within the following two to four weeks for comment on its accuracy. Following each interview I made a record, in a Word document in my project computer files, documenting my initial thoughts and reaction. This formed part of my reflexive account and included my comments on what surprised me about what was said, what was not said and other initial thoughts.

As the research interview was about the experience of the participants in research about back pain, I considered it relevant to offer to inform each participant's general practitioner of their involvement in the research, as I would have done for any patient involved in a health related research project. Where the participant wished for this to happen, I sent a courtesy letter to the GP giving some background information to the research and informing them of their patient's inclusion in the study. The GP contact details were given to me by the patient representatives themselves. Where patient representatives did not wish that their GP be informed,

no contact was made. I kept a record of the contacts I made with each of the patient representatives and documented these on a Patient Representative Interview Management Plan for each of them (Figure 10).

Patient Representative interview management plan		
Study Code: LIM/PR/ Phone number: Address:		
Task	When	Notes
Sent invitation letter		
Phoned to check received		
Consent received		
Interview date		
Location		
Confirmation letter sent		
Expenses discussed		
Wishes GP to be informed		
GP details		
Interview done		
Voice file download		
Transcription commenced		
Transcription complete		
Transcription to patient		
Comments from patient		

Figure 10. Patient representative interview management plan

3.5.2iii Stage Two: Sample – Group B

The case study sample which was the LIMBIC project was already defined and consisted of a range of types of data, all of which I was able to access in my role as LIMBIC project manager and researcher and for which ethics approval had been granted. The data related to the LIMBIC project which were specific for each patient representative included patient stories, transcripts of focus groups, interim reports, practice team improvement work, emails and notes from phone calls, photographs from the project wiki, the LIMBIC film and a further film involving one patient representative. This potentially allowed the research to explore data related to the eleven patient representatives and was able to generate a sample size in excess of one hundred separate items of data.

3.5.2iv Stage Two: Data Collection - Group B

For the collection of data for Group B the focus was on the data that were specific to each individual patient representative and which had originated from them. The data were already available from the LIMBIC project and the relevant data were identified at this point and later analysed with the semi structured interview data. See Table 5.
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D2.1.1	Patient stories	Stage Two
D2.1.4	Transcripts of Focus Groups with practice teams	Stage Two
D2.1.5	Interim review reports	Stage Two
D2.1.7	Practice team improvement project work	Stage Two
D2.1.9	Emails, phone calls, notes from correspondence	Stage Two
D2.1.11	LIMBIC photo gallery	Stage Two
D2.2.2	LIMBIC film – A Day at the Races	Stage Two
D2.2.4	Filmed interview about the experience of user involvement in research made by Health Foundation	Stage Two
D3.1 & D3.2	Semi structured interviews	Stage Two

Table 5. Stage Two of the study; data sources

As for Stage One of the study and the interview data from Stage Two of the study, these data were stored in folders in the research folders of my computer ready for subsequent analysis and a study code was allocated to each item of data and each folder. Once all the data that were required had been collected for this second stage of the study, the analysis process for Stage Two of the study began.

Summary of Stage Two

By using semi-structured interviews, analysing them thematically and using data related to each patient representative during their experience of involvement, and integrating and analysing these data together I hoped to be able to see the development of themes which would form the basis for the findings (Bazeley 2009).

3.5.3   Stage Three of the Study

The purpose of Stage Three of the study was to seek further data to use in triangulation and to seek additional data which could verify or challenge my observations from Stages One and Two of the study. I aimed to identify any patterns

and to make comparisons and contrasts with the data from different stages of the project and from different data that were collected in different ways. The aim was to draw upon the data from the LIMBIC project that did not relate specifically to each patient representative. Most of these data did not contain material that allowed the patient representatives to be identified. The data related to the delivery of the LIMBIC project including some of the dissemination activity such as conferences and published material.

3.5.3i Stage Three: Sample

The data from the LIMBIC project that related to patient representatives but which was not specific to each particular patient representative made up the sample for Stage Three of the study. These data included workshop presentations and hand-outs, workshop feedback evaluation forms, the project wiki, notes from patient representative meetings, workshop reflections, several dissemination and learning events and a number of reports and publications. Being able to draw on data through a range of sources from the processes of the LIMBIC project in which the patient representatives had been involved created a wide range of data which could be used in triangulation at the later stages of data analysis.

3.5.3ii Stage Three: Data Collection

Data from Stage Three of the study were drawn from the processes which formed the LIMBIC project and are illustrated in Table 6.
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D1.4	Support information for patients and practices	Stage Three
D2.1.2	Workshop material	Stage Three
D2.1.3	Workshop Fast Feedback	Stage Three
D2.1.6	Wiki	Stage Three
D2.1.8	Patient representative pre-workshop meetings	Stage Three
D2.1.10	Reflections on the Workshops	Stage Three
D2.2.1	Learning event	Stage Three
D2.2.3	LIMBIC illustration	Stage Three
D2.2.5	Celebratory and Dissemination event	Stage Three
D2.2.6	Conference posters and presentations	Stage Three
D2.2.7	Papers and publications	Stage Three
D2.2.8	Advising commissioners	Stage Three

Table 6. Data from Stage Three of the study

As in Stages One and Two of the study, study codes were allocated to each group of data which were used as labels for the data and each of these was saved in the research computer data files. These data are described below.

D1.4. Support information for patient representatives and practices
The information provided for patient representatives and practice teams consisted of a patient information pack, a practice information sheet and a patient information pack from INVOLVE. This supporting information was provided at the recruitment stage in hard copy format and on the project wiki.

D2.1.2 Workshop Material
The eight workshops comprised a mix of taught sessions, role play, small group work, discussion, project work, improvement activities and each one had supporting documentation associated with the activities for the day.

D2.1.3 Workshop Fast Feedback
A fast feedback evaluation form was completed by each participant at the end of each workshop. This aimed to contribute towards a brief evaluation of the session and give the research team an opportunity to make changes to subsequent workshops where possible. As project researcher I had written a report summarising all of the participants' comments and I used these reports in the analysis.

D2.1.6 Wiki
The wiki was used as a communication tool and repository for improvement tools and workshop material during the course of the workshops. The site is no longer in use as the project is now complete, but there is a link from the LIMBIC project website to the wiki. Using a wiki was a new experience for all the users in the LIMBIC project. All practice teams including patient representatives were invited to join the wiki.

D2.1.8 Pre-workshop meetings for patient representatives
The pre-workshop meetings were run specifically for patient representatives by the research team on the morning of each workshop. The facilitator of the sessions was a member of the research team. Sessions were held to support patient

representatives in their role. Notes from these meetings were used as data for this part of the study.

D2.1.10 Workshop reflections

Reflections were sought from all participants at the end of the project at Workshop Eight in the form of individual and team reflections. This feedback was in hard copy format for each participant. Forms completed by patient representatives were extracted and included in this analysis.

D2.2.3 LIMBIC Illustration

The LIMBIC research team commissioned a strategic illustrator to create a visual representation of the LIMBIC project and this took place on the day of the filming event of the LIMBIC film – A Day at the Races in July 2009. I provided the artist with information about the key stages of the LIMBIC project and sent data from the project that we had agreed might be most useful to influence a creative visual record of the project. The illustration was copied and reproduced in A4 format and shared with participants and stakeholders of the LIMBIC project. The illustration was also featured on the LIMBIC website and a copy of this is shown in Appendix 8.

D2.2.6 Conference posters and presentations

A number of conference posters and presentations were made as a result of the LIMBIC project; some were made by patient representatives or were about the patient involvement experience. These documents and posters were included in Stage Three of the analysis. They were:

- INVOLVE Conference 2008
  Patient involvement in managing back pain in primary care
  Poster and poster presentation (2 patient representatives)

- Folk.Us - User Involvement Conference 2010
  Presentation of the LIMBIC illustration
  Poster presentation (2 patient representatives and project manager)

- Learning from the LIMBIC project – a master class for primary health care teams 2010
  The patient experience
  Oral presentation (a patient representative)

- INVOLVE Conference 2010
  Public involvement in research: innovation and impact - one oral
  presentation and one poster presentation
  1. Presentation of the LIMBIC film - A Day at the Races
     (A patient representative, a researcher) Paper presentation
  2. "It didn't begin as a research project about involvement…"
     (Four researchers) Poster presentation

- Authenticity into Action 'Rhetoric or Reality' Critical perspectives on service
  user and carer involvement in education for health and social care
  Conference, University of Central Lancashire, June 2011
  Learning about quality improvement in interprofessional teams – service
  users and healthcare workers learning together about improving primary
  care management of back pain.
  Showcase presentation (One patient representative, one researcher)

D2.2.7 Papers and publications

Patient representatives were invited to provide their comments on abstracts which
were submitted for publication in academic journals and were involved in the
production of other material for publication:

- Campion-Smith, C. and the research team, 2009. Stop trying to cure us and
  start listening, *BackCare Journal for professionals who manage and treat
  back pain*, Winter 2009/10, p16-19.
- Andrews, M., 2009, Getting involved in back pain research – a patient
  perspective, *BackCare Members Bulletin*, November 2009 p4-5.
- Williams, S. and Worswick, L., 2010. Involving patients can change practice,
  INVOLVE Newsletter, Winter 2010/11 p8-9.

2.2.8 Advising commissioners

There were several initiatives in which patient representatives from the LIMBIC
project were involved in giving their advice to commissioners of health services
about the needs of patients in relation to back pain. One of these initiatives brought
together health care professionals and managers from primary and secondary care
and invited patient representatives from the LIMBIC project to bring their opinions
into the discussions about implementation of the recently launched NICE Guidelines
for the management of back pain (NICE 2009). The event was held at a
neighbouring academic institution and drew together a range of stakeholders. A
programme of the event and an evaluation report were made available by the host
institution.

Summary of Stage Three

Using material from the workshops of the LIMBIC project and some of its outputs, a broad range of data sources was brought together for subsequent analysis. The analysis of the data from Stage Three of the study is reported in the next chapter with the findings. Following this, the next stage of the analysis was to integrate the data from all three stages and undertake further analysis which is reported in the next chapter.

3.6   Summary of the research design

This chapter has presented the planning, design and methodology for the study based on Patton's (2002) framework for research design to address the relevant aspects of this research. I have also used ideas from other researchers for a theoretical framework (Morrow et al. 2012), and have taken a pragmatic approach towards the philosophical and methodological frameworks for this study (Creswell 2014; Johnson and Onwuegbuzie 2004). Ethical considerations have been discussed in relation to requirements in advance of undertaking the research and I have outlined my own philosophical assumptions which are likely to have influenced the research. I have also discussed the ways in which I have attempted to ensure rigour and trustworthiness in this study. I have tried to take an inclusive approach in discussing all of the issues relevant to the research design and illustrating evidence for my chosen approach by reference to the relevant literature. Appendix 7 illustrates the detail of the planning for analysis in the data analysis strategy.

4.   Analysis and findings; becoming part of behind the scenes

This chapter details the process and outcomes of the analysis of the data from the three stages of the study. Firstly, the findings from each separate stage of the study (Stages One, Two and Three) are presented. Findings from Stages One, Two and Three are then integrated and detailed in terms of emerging themes. These themes are then presented in Chapters 5, 6 and 7. This process illustrated patient representatives observing primary care teams in their work like actors on a stage and, as their involvement progressed, they gradually became part of behind the scenes. They developed a sense of belonging to the team. A flow chart on the following page (Figure 11. Data sources and analysis processes) illustrates the data sources and methods of analysis for each item of data from each of the three Stages.

LIMBIC STUDY

THIS STUDY

Data source   **Method of analysis**   **Method of analysis**   **Data source**

Stage One

Award scheme guidance for LIMBIC project

Thematic content analysis

Integrated with Stage Two data

Stage Two

Patient stories

Transcript of LIMBIC film

Interim review

Improvement projects

Emails

Phone calls

Photographs

Thematic analysis

Thematic content analysis

Visual content analysis

Individual thematic analysis

Collective thematic analysis

Semi-structured interview transcripts

Integrated and re-analysed with all Stage Two data

Stage Three

Workshop material

Fast feedback

Wiki content

Meeting notes

Dissemination events

Commissioning event, posters and publications

Focus group transcripts

Reflections

LIMBIC illustration

Thematic content analysis

Thematic analysis

Visual content analysis

Integrated and re-analysed with Stage Three data

Final Study Findings
Integration of primary interview data and secondary analysis of Stages One, Two and Three (LIMBIC) data

Figure 11. Data sources and analysis processes

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4.1   Analysis and Findings from Stage One of the Study

This stage of analysis used documents to explore the purpose of involving service users in the LIMBIC project.

D1.1   Call for Research Proposals

This group of data consisted of; a Call for Outline Proposals, Specification for Full Applications, Guidance on completing the application form, Guidance about the evaluation of the scheme and a list of Frequently Asked Questions (FAQs).

These documents stated the awarding body's expectations that patients were to be involved in the project and they gave examples of how this might occur. There was no indication of their expected outcomes or impact. There was an expectation that research teams would have previous experience of working collaboratively with patients and of recruitment and selection processes. There was no clear rationale for patient involvement or its proposed impact. The need to support patients was recognised by the funding body but there was no guidance about what support might be offered. There was no reference to evaluation of patient involvement in the overall evaluation of the award scheme. The awarding body seemed not to anticipate queries about the patient involvement aspect of the scheme, nor the purpose of their involvement, their experience or their impact on the outcomes of the research. These aspects might be implicit but that is not certain.

I concluded that this group of data showed that the requirement to involve patients might be tokenistic. There was no requirement to evaluate the involvement of patients in the scheme.

D1.2 LIMBIC Project Research Proposal

The research team described seeking input to the proposal from a service user organisation, a UK national charity. They also described how the delivery of the educational intervention would be to a range of health care professionals from general practice teams including a service user. The team cited evidence of best improvement practice demonstrating their history of working together on improvement projects and drawing on evidence from the literature. The team

showed commitment to the involvement of service users, describing their previous experience of using patient stories and how they believed that the involvement of patients was central to delivering quality improvement and a crucial development aspect for all the practices involved in the project. They stated their "very strong commitment to, and experience in, developing innovative approaches to involving patients."

There was no reference made to the role of patient involvement in the practice teams in the section on the proposal about scale and transferability of the findings of their study. This suggested that the research team did not expect to involve patients in the project to influence the scale and transferability of the project findings. There was no measure of the patient involvement aspect of the project in the evaluation of the project aims. The team stated that they expected patients would influence the choice of topic for the practice improvement projects so that the improvement projects were about things which were important to patients.

The project proposal was a detailed, evidence-based funding application. The intended approaches of the research team for involving service users were clear and there was reference to the fact that involving patients would improve the quality of the improvement work being undertaken by the practice teams. There was no mention in the proposal that the team intended to evaluate the patient involvement aspect of the study as part of the overall evaluation. The impact of service user involvement was not part of the evaluation.

In summary, the project team was committed to involving patients but did not include plans for evaluating the impact of their involvement in their evaluation strategy.

D1.3 Evaluation of the Engaging with Quality (EwQ) Initiative

This report evaluated the award scheme, which had preceded the Engaging with Quality **in primary care** scheme. Award holders had been asked to describe how service users were involved in the design and delivery of their quality improvement interventions. The purpose of including this report in the analysis was to gain an understanding of the evaluation scheme for the LIMBIC project from the perspective of the external evaluator and so to identify the purpose of involving users in the

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EwQ **primary care** scheme. The aim of this was to gain insight into the expectations of the funding body, the award holders and the service users themselves for the EwQ primary care scheme.

Analysis of this document showed that the purpose of involving service users in the projects of the EwQ scheme was not made explicit. It was suggested that service users might have some influence on the project and award holders were asked to report on their processes for involving service users.

Summary of Analysis of Stage One

These documents associated with the design and planning of the LIMBIC project revealed that the funding body was committed to ensuring that patient involvement was integral to the award holders' projects, and yet they failed to state their intention for doing so. The LIMBIC research team demonstrated a deep knowledge of and strong commitment to involving patients in their study. They set goals for this process, such as recruiting a patient representative to each practice team and for patient representatives to influence the choice of topics for improvement projects, but they did not set goals for the impact of patient involvement on the project outcomes. Explicit aims for involving patients in the study were not made by either the funder or the research team, nor were details provided about the impact that service users were expected to have on the study outcomes. There were no plans in any of the documents for evaluating the service user input or experience.

4.2   Analysis and Findings from Stage Two of the Study

Stage Two of the study explored data related to the patient representatives and included the semi-structured interview transcripts, called Part A for ease of describing, and the data from the LIMBIC project that related to the patient representative, called Part B. Some of this section contains detail about the methods of data analysis as well as the process of analysis and findings, but is included here to maintain a consistent flow with regard to the management and interpretation of this stage of analysis.

4.2.1   Analysis and Findings: Stage Two Part A

The details of the sample for Part A, the semi-structured interviews with patient representatives, are shown in Table 7.

Code	Age	Gender	Employment status	Experience of working in health care
A	41-50	F	Employed unskilled	Yes
B	61-70	M	Employed unskilled	No
C	71-80	F	Retired unskilled	No
D	61-70	F	Retired professional	Yes
E	61-70	M	Retired professional	No
F	51-60	F	Employed professional	No
G	61-70	M	Retired unskilled	No
H	61-70	F	Retired professional	No
I	41-50	M	Employed professional	No

Table 7. Group A sample details

Eleven patient representatives were invited to participate in a semi-structured interview, two individuals declined leaving nine in the sample. One patient representative was a member of the LIMBIC project steering group. Table 8 shows anonymised data for the relationship of each patient representative to the LIMBIC practices and the stage at which they entered the LIMBIC project.

Information about the interviewees is provided in Section 4.2.1, Table 7. However, the nature of the sampling strategy necessitates that limited information is sometimes provided, to ensure participant anonymity. Specifically, participants had been assured of their anonymity in the presentation of any interview data but all participants were already known to the LIMBIC project research team and to the LIMBIC project practice teams, making it possible for them to identify individual participants, despite the use of pseudonyms. Participants had also appeared, and been identified, in the LIMBIC film and the LIMBIC masterclass. Consequently, where interview data links the participant directly to the film or masterclass, it becomes possible to identify that participant in the remaining data. For this reason, some interview data is not assigned to individual participants

In deciding to undertake semi-structured interviews with LIMBIC project participants upon completion of the LIMBIC workshops I suggested to the interview participants

that I might wish to return to them to seek a further follow up interview and that this might be after a further twelve months. This was to allow me to return to them to seek clarification around the initial findings from the data analysis. A clause in the consent process for the interview left this as an option. However more than two years elapsed between collecting the data in the interviews and analysing the data so that any follow up interview would have been subject to potential problems of recall and therefore reliability. At the time of analysing the interview data I was confident that there was sufficient data and that it was of adequate quality to be able to identify the themes that would lead to the findings that were presented. In relation to the data analysis and sample size, at this point I believed data saturation had been achieved. I also believed that returning to the participants to undertake a further interview more than two years after the initial data collection, and therefore three years after their engagement in the LIMBIC workshops, would not add new material to the themes that were becoming part of the findings.

Initial study code	Relationship to LIMBIC practices	Entered project	Interview given
Anon 1	Registered at and attached to Practice H	Workshop 1	Yes
Anon 2	Registered at and attached to Practice C	Workshop 1	Yes
Anon 3	Attached to Practice I, registered elsewhere	Workshop 3	Yes
Anon 4	From Back Club, not attached to a Practice	Workshop 4	Yes
Anon 6	From Back Club, not attached to a Practice	Workshop 4	Yes
Anon 7	Registered at and attached to Practice G	Workshop 1	Yes
Anon 8	Registered at and attached to Practice F	Workshop 4	Yes
Anon 10	Member of LIMBIC Steering Group	Workshop 1	Yes
Anon 11	Known to Practice E, registered elsewhere	Workshop 3	Yes

Table 8: Patient representatives association with LIMBIC practices

Practice teams B and D did not recruit a patient representative from their own practice but sought their patient advice from other patient representatives who were brought into the project at Week Four of the workshops following an open invitation to members of the local Back Club. Six practice teams, A, C, E, F, G and H recruited a patient representative from their practice population. Practice I recruited a patient who was related to a member of their LIMBIC practice improvement team and registered at a practice elsewhere, but in the same PCT locality. Two patient representatives were from the local Back Club and one was a member of the LIMBIC project Steering Group and had been recruited from the local Back Club, but was not attached to a LIMBIC practice. This person attended all the LIMBIC

workshops and supported practice teams in an advisory role as did the other patient representatives from the Back Club.

Some patient representatives joined the project at Workshop Three or Four due to the difficulties encountered by the practice teams in recruiting a suitable patient representative to join their team. This had consequences in relation to their ability to engage at the intended level with the practice teams because they had missed three or four of the workshops.

Semi-structured interviews took place between February and November 2009 and lasted between 37 and 76 minutes. Interviews were held at a location that had been mutually agreed between the researcher and the patient representative. Two of the interviews were held in a meeting room in the university. One interview was held in the workplace of the patient representative and the remaining six interviews were held in the home of the patient representatives (Table 9).

Patient Study Code	Interview date	Location	Duration	Time
A	18/5/09	Home	48 mins	17.00
B	9/7/09	Home	52 mins	11.00
C	2/11/09	Home	43 mins	10.30
J	12/6/09	Home	37 mins	14.00
K	28/4/09	Home	76 mins	12.00
L	7/5/09	Home	59 mins	19.00
M	3/4/09	University	59 mins	10.00
P	27/4/09	University	59 mins	10.00
S	25/3/09	Their workplace	48 mins	16.00

Table 9. Interview dates, location and duration

Voice files from the digital voice recorder were allocated a unique study code and downloaded into a folder on the researcher's password-protected computer. Interviews were transcribed within two to four weeks of taking place. Transcribing was undertaken by the researcher using transcribing equipment associated with the voice recorder. Recordings were transcribed verbatim. Completed transcripts were printed and sent to the interview participants, marked as confidential, as part of the member checking process. The interview participants were asked to agree whether they viewed the transcript as an accurate reflection of the interview and were offered the opportunity to retract any material. None of them did. All of them agreed the accuracy of their transcript.

Each interview transcript from Stage Two of the Study was analysed separately to begin. They were then analysed as a group together to begin to clarify the codes and categories I had assigned. Each set of data for each individual patient representative was then grouped alongside the interview data for each individual patient representative and analysed with the participant-specific data together as one group. The analysis of the data from Stage Two of the study was completed by integrating the data from across all the participants to produce themes from across all the data. The timescale for this process was three years. Interviews were undertaken and transcribed between March and December 2009 and a preliminary analysis was started at that point, but this was taken up again in June 2011 when the LIMBIC project had been completed. The timeline for the data analysis process for the semi-structured interviews is shown in Figure 12. Timeline for analysisFigure 12.

Figure 12. Timeline for analysis
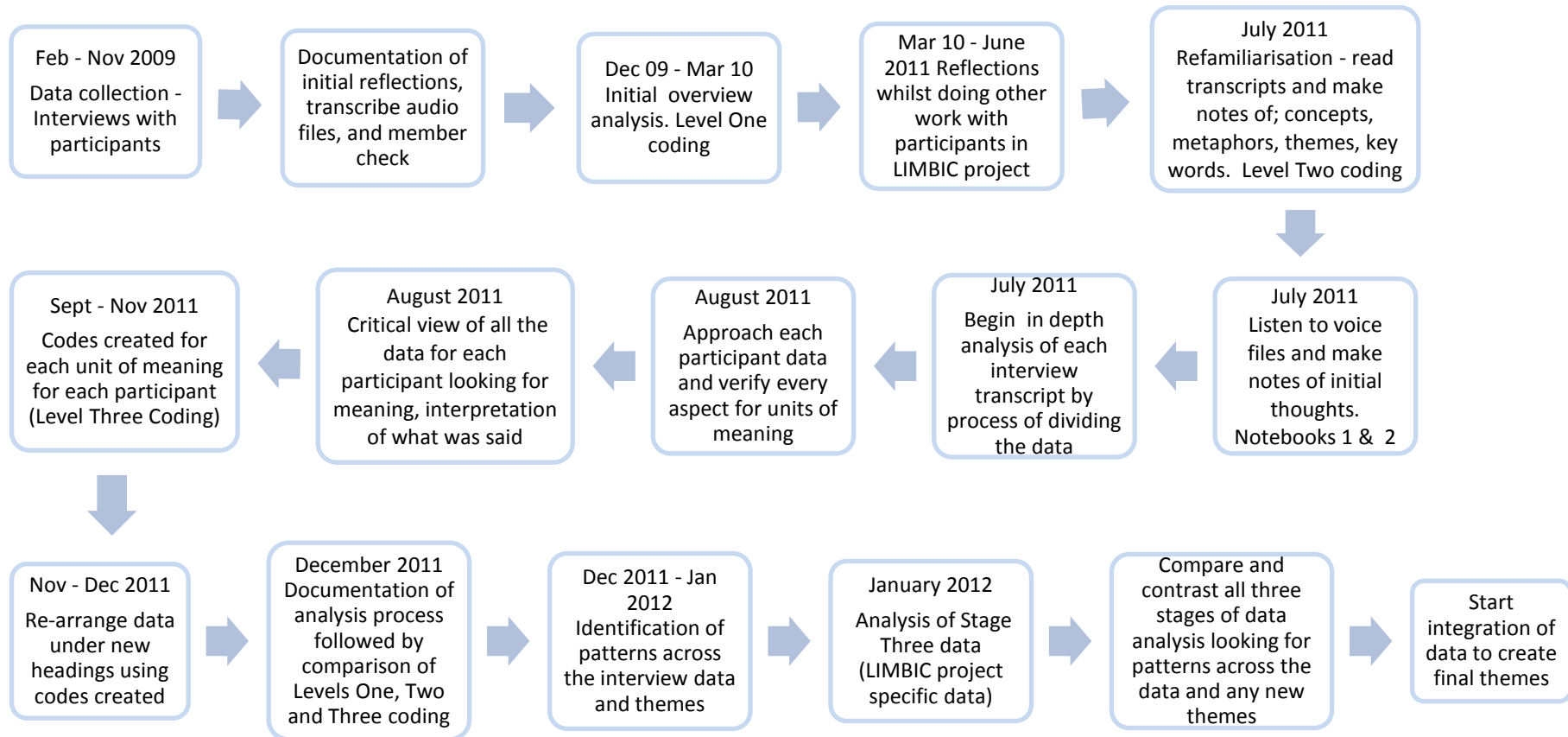
I began the analysis of the interview data by reading the transcript and listening to the voice file for each participant. I observed the detail of the narratives thinking about assigning codes and categories to the data and looking for patterns across these data. I worked across the data moving from voice file and word file through to organising the data into codes and then comparing codes across the transcript.

I took a pragmatic approach towards the order in which I listened to the interviews by listening to them in study code order, starting with LIMPR01 and then LIMPR02 and so on. I began the analysis by first of all listening to the voice recordings of each of the interviews and then reading the transcript of each interview and I made notes of notions and ideas that came to me. This enabled me to obtain an overall sense of the data. Listening to the transcripts allowed me to develop ideas for codes for the data. This took pace in June 2011, two years after I had initially undertaken the interviews. I had delayed continuing the analysis of the interview data because I was working alongside some of the patient representatives from the LIMBIC project on dissemination activities and I felt that this proximity to the participants might influence the way I would look at and analyse the data. As I listened to the voice files I made notes in a notebook recording the words that participants used that related to how they felt and words that described their experience. After listening to each interview I listened to my own recorded comments that I had made about my initial impression from the time I had carried out the interview. I made notes about what I felt then after listening to these comments again. Some of the initial thoughts had faded a little in my memory and I found it useful to remind myself of these.

I completed my first round of listening to the voice files and researchers comments between 1 June and 1 July 2011. I began to get ideas about themes which might provide a structure for the codes and I made notes alongside my handwritten notes in my notebooks. Next I read through the notes I had made whilst reading the interview transcripts. By 1 July 2011, I had listened to each of the voice files and made hand written notes in two A5 note books. My notes documented my thoughts upon hearing some parts of the interviews and some notes were verbatim sections of the interview which I felt were significant and may be relevant to the analysis.

On 3 July 2011, I began to read through the notes I had made after each interview at the time of the interview in 2009. I then looked back at my initial notes from July 2009 about the initial identification of codes from the first six interviews. I found that

the codes were similar to those I was beginning to develop in my mind now, and in my note books from having listened to the interviews again. Next I read through the notes I had recently (July 2011) made in my notebooks after listening to the voice files. I began to jot down words and groups of words which might become the codes I could work with for the next stage of the analysis. I was getting a sense that there were common words and meanings across the transcripts and some clear categories were developing.

A few weeks later I re-read the transcripts making notes on the transcript in the left hand column where the words on the transcripts related to a code and I also made notes in my code book of ideas for new codes that had not previously occurred to me. I assembled the words, phrases, codes and ideas into three documents to help me get a clearer idea of the themes I would be using for the next stages of analysis. I created three Word files:

- one file contained a list of ideas that might become my working codes. I had initially, naively, called these 'themes;'

- one file was a list of words that I felt were important when I read the transcripts and which might fit within each of the codes, 'Words and phrases;'

- a list of words used by the participants to describe their experience was also created – 'Patient reps experience.' I had begun to see some words repeated frequently and wanted to record this.

As I progressed with this, it became easier to work with the codes and I was able to order the words and phrases within the codes which helped me to redefine the name for a particular code in some circumstances. For example I began with a code called 'another perspective' and developed this code to call it 'different perspectives.' I began with separate codes for 'equal' and 'valued' and then merged these and some other phrases into an overall code 'shared values.'

Steering Group member interview

A member of the LIMBIC project steering group worked closely with the patient representatives during their engagement with the practice teams throughout the workshop series. This individual worked for a national charity advising people about

back pain. I considered undertaking a research interview with this individual to explore another perspective, especially around the group dynamics of the patient representatives and to explore further this individual's experience of working with the group. I hoped this might be useful in triangulation of the data during analysis. I also considered whether I would require NHS ethics approval to undertake this further interview but, after discussion with my supervisors, concluded this was not necessary as the individual was not a patient of the National Health Service, in the capacity of Steering Group member.

This semi-structured interview with the steering group member took place in July 2009. In advance of the interview I had mentioned to the individual the purpose of the interview and the individual had verbally agreed to participate. I prepared a participant information sheet and consent form, adapted from the patient information sheet I had used with patient representatives, to reflect the different status of the participant (who was not a patient representative) and made this available by email to them in advance of booking the interview time and date. I made contact one week after sending the information sheet and booked a time to undertake the interview at a mutually convenient time in the workplace of the participant.

The interview record, consent process, study coding, digital recording, transcribing and sharing the transcript with the participant, for confirmation of accuracy, all took place in the same way that it had for the patient representatives' interviews.

The description of the analysis and findings of the interview data continues when it is integrated with data from Stage Two Part B from the LIMBIC project in the next section.

4.2.2 Analysis and Findings: Stage Two Part B

Stage Two included the analysis of a group of data related to the LIMBIC project which was specific to each patient representative, such as excerpts from focus group transcripts, patient stories, entries on the project wiki, reflections and visual material such as photographs and films. The existing datasets were used to confirm or discount new findings and to suggest patterns beyond the scope of the semi-structured interview data sample. The analysis of the visual material is explained first.

Analysis of visual material

The visual material requiring analysis included two films and a photo gallery on the project wiki. I sought advice from an expert who was a colleague in the Media School of the University to help in deciding on the approach to analysing this material. There were various possible approaches to analysing the visual material which I could have taken. For the photographs, I took into consideration the fact that the photographs were of people and places known to me and the setting and context were familiar. I decided the photographs could add to the research by bringing data that might not have otherwise been available. These were visual representations of individuals set in a time and a place. I placed copies of photographs in the folder of data for each patient representative and analysed these together with the group of data for each patient representative. When the coding framework was being developed, I placed codes alongside the photographs which represented what the photographs told me about what I saw. For example, I saw people talking together at ease, I saw how people looked in group situations and I saw patient representatives working together as a group and working in groups with their practice teams. I noticed who was absent from the photographs. By including the analysis of these visual data in the coding framework I added richness to the data for further analysis.

To analyse the film (LIMBIC 2009), I knew that because I was present during the making of the film and I was familiar with the purpose and content of the film, I would not be viewing it as a newcomer to the material. I decided to analyse the film by transcribing the verbal content, that is making a written record of the sound track of people's conversations, and I included this textual data in the analysis of the data for each participant. I therefore produced a transcript of the narrative from the film. For each participant I extracted content from the film transcript in which they spoke or in which their character played a part and placed this textual data with their other data in their data folder, ready for continuing the thematic analysis. The data were therefore grouped for each participant and analysed with the remainder of the data for each patient representative.

Analysis of participant-specific data

The LIMBIC project data for this (Stage Two of the study) part of the analysis were related to each individual patient representative and had originated from them. I grouped the data from Stage Two of the study by individual patient representative,

creating a unique group of data that was specific for each of them. Approaching the data in this way permitted me to develop a rich picture of data for each participant to add to the interview data so that they could all be analysed together. The re-grouped data were saved and stored as shown in Figure 13 below.

Figure 13. Screenshot of grouped Stage Two data

A folder was set up containing all of the sources of data relating to each individual patient representative from Stage Two of the study as shown in the example, for patient representative number LIMPR03 in Figure 14.
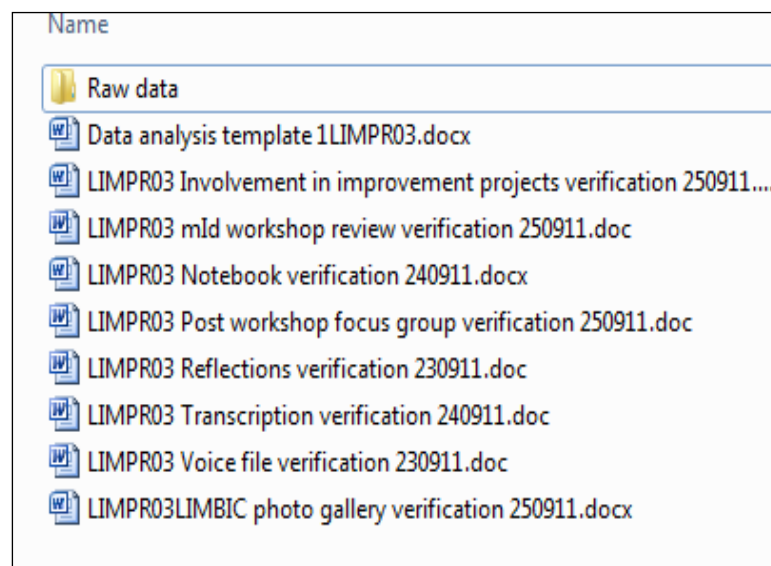
Figure 14. Screenshot of folders of data for participant LIMPR03

I then approached each set of grouped data for each participant to verify that all the content for each item of data had been assigned a unit of meaning to add to the analysis. I verified all the data for each participant. Beginning with participant LIMPR01, I read through the transcript, then I listened to the voice file, then I read through the transcript at the same time as listening to the voice file. I read through the reflections I had documented at the time of the interview, then I read through the notes I had made the previous month (July 2011) when reading through the transcript. I read the notes I had made from the various telephone calls with LIMPR01, the transcript of the patient story, the transcript of the post workshop focus group interview with the practice team and the report of the practice improvement projects from the practice team.

Templates were created for recording these verifications as they were undertaken for each participant's data and for each of the data reduction summaries and codes assigned. From working through this process I was able to draw up a summary list of codes for the next stage of analysis. See Figure 15.
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CODES after verification - Participant LIMPR01

Beliefs, believing, not being believed, being believed (added 20/9/11)
Realisation
Differences, barriers, difficulties
Learning community, being part of something bigger, something important
Experience of participation
Concern for others
Helping others
Altruism
Respect
Acceptance
Acting, roles, exchanging roles, pretence, knowing what role they are in?
Feeling valued
Feeling important
Feeling fortunate, feeling lucky
Feeling different, we are all different
Busy practice, busy doctors, busy workload
Time to listen, listening
Feeling pain (added 25/8/11 after including analysis of patient story)
Nobody knows what it's like, they don't understand (added 20/9/11)
Relationships (added 2/9/11 after analysis of post workshop focus group)
Commitment (added 20/9/11)

Figure 15. Codes assigned after verification

```
┌─────────────────────────────────────────────────────────────────────────┐
│                Data analysis template  – individual participant            │
│                                                                            │
│ Study Code             [removed]                                           │
│ Interview date         xx April 2009                                       │
│ Transcription          19 May 2009                                         │
│ Member check           2 June  2009                                        │
│ Analysis process       June – August 2011                                  │
│                                                                            │
│ Data reduction and verification for units of meaning                       │
│         Voice file                      [date removed]                     │
│         Transcription                   [date removed]                     │
│         My reflections                  [date removed]                     │
│         My notes (Notebook 1)           [date removed]                     │
│         Patient story                   [date removed]                     │
│         Mid workshop update             [date removed]                     │
│         Post workshop focus group       [date removed]                     │
│         Practice improvement project    [date removed]                     │
│         LIMBIC Film                      [date removed]                     │
│         LIMBIC wiki photo gallery        [date removed]                    │
│                                                                            │
│ Verification:                                                              │
│ There are repeated elements to X's story verified across several items of  │
│ data and these include the turning point at [one] presentation, the        │
│ openness of it all, togetherness, being given the opportunity and time to  │
│ talk about their story. X grasps the importance behind patient involvement │
│ saying that it would not have achieved what it did if it weren't for the   │
│ patients. X's role [an aspect of the project] shows an example of;         │
│         a) Patients taking control in their involvement role               │
│         b) Understanding how a GP should talk to a patient                 │
│         c) What the primary care management of back pain involves          │
│         d) Empathy                                                         │
│ X talks about going to the workshops as an empathising experience. It was  │
│ all very equal and open-minded. This is shown also in the photos in which  │
│ X appears. X seemed surprised that they were interested in what they had   │
│ to say. X sees general practice as having limited time to spend with       │
│ patients and they should look holistically at their patients. X comments   │
│ that more effort and resources are put in to other conditions such as      │
│ cancer (participant Y says this later). The health service has a long way  │
│ to go before it gets its services right for patients. [X's] story          │
│ demonstrates this.                                                         │
│                                                                            │
│ Contradiction:                                                            │
│ X spoke about one of the other patient representatives whom X hadn't got   │
│ on with because Z dominated the group sessions. Z didn't think so in       │
│ [their] interview). During the mid-way interim review X wonders whether    │
│ [they] have too high expectations of [their] GP. This doesn't appear       │
│ elsewhere. "I was pleased to do it, although I feel as though I'm an        │
│ irrelevance." (interview) This does not appear elsewhere. [removed example │
│ which identifies the participant]                                          │
│                                                                            │
│ Potential nuggets:                                                        │
│ "Pain is in the brain. It's how you manage it." (notebook comments on      │
│ transcript p21)                                                           │
│ "Togetherness I suppose" (notebook p21)                                   │
│ With regard to the experience of voicing [their] view in the group [they]  │
│ talked about [their] apprehension about speaking and wondering whether     │
│ what [they] said would be relevant.                                        │
│ "I felt that was a turning point for me" (xx's presentation).              │
│ "I don't want to be a patient, I need out from the doctor" (interview)     │
│ [removed further examples which might identify the participant]            │
└─────────────────────────────────────────────────────────────────────────┘
```

Figure 16. Template for verification of participant specific data

I created a template for recording the verification processes (Figure 16) I had used for the first participant and replicated this for each patient representative. This allowed me to ensure I had used the same processes for analysing each set of data for each participant and it created an audit trail for my analysis processes. A hard copy of each participant's data was saved in its own separate hard copy folder.

I coded all of the data for LIMPR01 including my observations and transcription of the LIMBIC film. After I began the data analysis for LIMPR02, I was able to add further codes to this list. After the voice file verification and the transcript verification I added 'being helped, supported', 'giving help/receiving help' to the 'helping others' code. I also added 'equal' to the 'feeling valued' code, I added 'being listened to', 'hearing' to the 'time to listen' code, I added 'being in pain' and 'back pain' to the 'feeling pain' code and I also added a new code 'open/honest. I returned later to the transcript for LIMPR01 to re-code the data after I had completed coding all the data for LIMPR02. I then coded all of the data for the remaining patient representatives in the same way, allocating a code to each unit of meaning that I had identified for each item of data. Figure 17 shows a computer screenshot of the list of codes.

Name	Date modified
Re-coded	26/09/2012 10:57
Acceptance.docx	21/11/2011 08:59
Beliefs.docx	21/11/2011 08:59
Busy practice.docx	21/11/2011 09:00
Commitment.docx	21/11/2011 09:01
Concern for others.docx	21/11/2011 09:01
Differences.docx	21/11/2011 09:02
Experience participation.docx	21/11/2011 09:03
Feeling different.docx	21/11/2011 09:03
Feeling pain.docx	21/11/2011 09:06
Feeling valued or equal.docx	02/12/2011 13:52
Help and helping.docx	21/11/2011 13:49
Learning community.docx	21/11/2011 13:50
Nobody knows.docx	21/11/2011 13:50
Open honest.docx	21/11/2011 13:51
Realisation.docx	21/11/2011 13:52
Relationships.docx	21/11/2011 13:52
Roles.docx	21/11/2011 13:53
Time and listening.docx	21/11/2011 13:54

Figure 17. Screenshot of Level One codes

I acknowledge Stake's (2000) belief that when codes get too complicated even experienced researchers cannot find what they know they have stored. Over the next two months I continued to methodically code each item of data for each set of data for each participant. As I completed coding all of the data related to an individual participant I undertook a verification process using the analysis template (Figure 16). I made observations about where data from participants were similar and where there were contradictions. I then made observations about where I had identified patterns across an individual and where I found new meaning from this part of the analysis process. I developed the initial codes from reading of the transcripts and listening to voices files and studying the associated patient representative documentation. I then began to make comparisons across individual data sets. I had developed a summary for each individual participant and I now looked across these data for similarities and differences in the data across participants. I looked for patterns across these data which might contribute to themes. My approach of inductive analysis aimed to discover patterns, themes and categories across the data. Reading the compilation of the summaries of all the individual participants' data, but now looking through the lens of a newly developed code, I began to observe the emergence of themes in the data (Figure 18).

'Themes' from level one coding
Communication   • Language and how we use it   • Communication about expectation   • Communication about caring   Influencing change   • A shift in the balance of power   • A shift in attitudes, beliefs and perceptions   • A shift in understanding   • A shift in behaviour   Belonging to a community   • Learning environment, learning experience   • A community of people with pain   • Culture of the community   • Being creative   • Similarities and differences, overcoming tensions   • Sharing experiences

Figure 18. Themes from Level One coding.

The analysis of the participant specific data led to the identification of patterns across the categories of data which in turn led to the development of several key themes. There was a theme about how people communicate and the importance attributed to listening and hearing as well as the articulation of expectations and caring. A second theme was about influencing change and the observation of shifts in attitude, beliefs, perceptions, understanding and behaviour and an overall shift in the balance of power was evident. A third theme described the sense of belonging to a community which had its distinct culture and contained a sub-culture community of people with pain. Members exhibited creativity and described learning experiences and sharing experiences which included the identification and resolution of differences. These early themes were later reorganised and re-ordered.

I went on to reorganise the summaries of the level one coded data to re-code it against each of the themes that I had identified (see Figure 18). I continued to develop the thematic analysis by reflecting critically upon the emerging findings and linking themes across the data.

Summary of analysis of Stage Two

By using semi-structured interviews, analysing them thematically and using data related to each patient representative during their experience of involvement, and analysing these data together thematically I was able to develop initial themes which were to form the basis for the findings of this research.

4.3   Analysis and findings from Stage Three of the Study

The analysis process continued using a combination of methods of analysis from Stages One and Two of the Study. The data from Stage Three were documents from the project which were generic in nature compared to those documents from Stage Two. They were not specific to each patient representative, but reported generally on the project's processes and outcomes. Project documentation was reviewed for evidence that was relevant to the patient representatives and codes were applied to these data after they were reduced to a unit of meaning for each relevant item of data. I already knew the codes I had assigned to the data from

Stages One and Two when I approached this stage and so the analysis process built upon these codes. I was able to verify content as I saw relevant data which led to a different feel for the analysis process. It had moved to another level of analysis as I applied data to codes that had already been developed and where themes were already emerging. The individual groups of data for Stage Three are now discussed.

D1.4 Supporting information for patient representatives

The introduction to the patient representative information pack explained that they would learn from the practice team and it outlined what could be expected, both for practice teams and patient representatives. Extracts from this document are used here to illustrate the relevant supporting information that patient representatives had received:

> "By participating in the study, the patient representative will play a key role in a large healthcare improvement project and will benefit from a learning opportunity. They will work together with the primary care professionals as a team on the project and may benefit from what that experience brings. They will have the opportunity to share their own perspective as a user of the services by sharing their experiences about the care they have received. The project as a whole may provide information that helps to improve the treatment of other people with back pain who seek advice from their GP."

The information pack explained the reasons for involving patients in the study:

- "to improve treatment services for themselves and those who come after them, for many people research may be a means to an end and they are likely to want to know what will happen as a result of research,
- to identify problems related to the treatment or service they are offered,
- to influence the research agenda in a way that makes research more effective,
- to identify gaps in knowledge related to specific treatments or conditions which they feel need research,
- to ensure that the issues which are a priority for people are addressed,
- to ensure that future research is relevant to the needs of a specific group of people,
- to identify existing research which is not being disseminated or implemented, which could improve treatments or services,
- to ensure that research is undertaken in an ethical way."

All patient representatives were provided with this tailored information pack and it was also posted on the project wiki. Patient representatives also all received an INVOLVE Patient Information Pack (2006).

Guidance was clear about what patient representatives might experience by engaging with the project. It stated that they would benefit from a learning opportunity, and might benefit from what that experience might bring. The reasons for involving patient representatives in the study were made clear to them.

I cannot be objective in my description of this documentation as I designed the information pack which was subsequently approved by the research team for use with patient representatives. The advice source used was INVOLVE (2006) and as such it was relevant and up to date at that time in relation to user involvement in UK health and social care research.

D2.1.2 Workshop Material

I reviewed these documents and PowerPoint™ files to help me understand what patient representatives were experiencing in terms of their learning in the workshops and any influence they may be exerting on the progression of the improvement projects. The summaries of the programme content and brief reports helped me to develop a picture of the progress of the learning journey experienced by all the workshop participants. The importance of team work was a key message and one which all participants were exposed to by being encouraged to work as teams throughout the workshops, in a variety of roles and situations. The workshop design and content illustrated a commitment to achieving an impact on patient care as a result of involving patients in the project.

There was emphasis on encouraging inclusion of the patient representatives in the practice team activities. A door was opened for them. Patient representatives were empowered to vocalise their opinions and the research team was responsive to them. Late joiners to the project felt compromised and they had reason to; they had missed a lot of content, learning, bonding and team building activities.

I deduced that the workshop content, design and delivery impacted on the patient experience in several ways. A climate for open communication was created and the approaches used in the design of the workshops allowed sensitive issues to be

discussed in a non-threatening way and different perspectives became obvious. These were around the experience of back pain, the support that patients wanted, the support they needed from the practice team and the importance of effective communication, including listening. These discussions were facilitated through the use of patient stories, group discussion, the use of feedback, a presentation by a patient representative and talks from external speakers.

Looking back over the workshop delivery, there was an increased level of understanding on the part of the patient representatives and this included the development of trust, openness and increased confidence. As this was happening with the patient representatives, it was probably occurring with the practice teams too.

D2.1.3 Workshop Fast Feedback Forms

Patient representatives consistently reported getting a lot out of the workshop sessions. They also requested more time be set aside for their morning meetings. These sessions were valuable to them. They described them as mentoring sessions. I summarised the early 'themes' that I began to identify at that time.

Key 'themes' emerging from patient feedback

A shift

Over the course of the workshops the practice teams started to comment on the value of involving patient representatives in the workshops. Participants became more relaxed as the programme of workshops progressed and there was a shift in their thinking about patient involvement as the healthcare professionals and patient representatives immersed themselves in the shared learning processes that were being achieved as the workshops progressed.

An openness

The environment was very open. Participants were comfortable working with one another despite some initial reservations about this. The atmosphere was relaxed and neither patient representatives nor healthcare professionals seemed to feel any boundaries around what they felt they could say, except for example where ground rules might be breached by people using jargon. Patient representatives offered open and honest feedback to the research team and where suggestions had been

made, these were acted upon where possible, for example designing a session for patient stories and providing a summary workshop report for those unable to attend.

Being equal

Patient representatives learnt from the presentations about back pain and about improvement and said they enjoyed working with the practice teams. There was no sense of any hierarchical structures dominating the flow of ideas and learning. The language used in the feedback suggested participants felt equal to one another, offering ideas and opinions and listening and hearing in turn.

Patient representatives were accepted into the group of healthcare teams with a welcoming approach and all parties responded by working together and at a very early point, learning to listen to one another. The research team played their part in role modelling the important attributes of team working for example, by implementing changes based upon participant feedback, showing how they had listened. The delivery of the patient stories by the patient representatives was a key focal point in the "shift" of attitude towards the value of patient involvement. The presentation by the pain management specialist influenced all who heard it and participants started to open the debate about not getting better and self-management of chronic pain.

D2.1.6 Wiki

In using the wiki as a new and novel tool there were some initial problems encountered by users but, in spite of this, they found it useful. All but two of the patient representatives registered to use the wiki. Three reported that they found it helpful and liked using it. Two others reported that they did not post any messages on the wiki but they found it a useful tool. The wiki has relevance for the research question in that it shows that there was inclusivity in relation to patient representatives in the practice teams, and for three of them they liked working with the wiki.

D2.1.8 Pre-workshop meetings for patient representatives

The pre-workshop sessions provided opportunities for identifying issues for further discussion and reflecting on previous learning so that they could go into the next workshop and gain further knowledge as well as contribute effectively. The sessions helped them gain a better understanding of the project, the role of the practice

teams and the role of the patient representatives in participating in the improvement work.

D2.1.10 Workshop reflections

Reflections were recorded at the very end of the series of eight workshops. The morning sessions were found to be very helpful, for example when the discussions from the morning session were taken forward to the afternoon workshop session. The information provision was welcomed and participants liked using the wiki. Patient representatives felt involved, they felt there had been a lot of benefit and they were now more aware about the processes for provision of back pain care. They said they understood more about the importance of taking responsibility and managing their condition. They said they had observed that there had been a great deal of key learning for many of the professionals.

Being listened to and being invited to speak about their condition were appreciated as was the importance of getting good information at the start, including clarifying their understanding, the timescale and knowing what was involved.

Aspects which could have been improved included making sure that all the speakers involved the patients and avoidance of jargon. At the beginning the patient representatives did not always have the confidence to speak out or challenge and those who were not from a LIMBIC practice felt left out and less involved.

Some patient representatives expressed their interest in continuing their involvement in the LIMBIC project after the workshops were finished. Overall, the patient representatives demonstrated a good understanding of the project, what it entailed for the practice team and how the improvements were being effected at their practice.

Being able to have a voice, being invited to speak individually about their experiences with back pain, and taking part in the discussions were highlighted as positive. One patient representative said that the best thing for them was the realisation that the self-help aspect of back pain was more important than many professionals realised. When asked about challenges, the patient representatives were hesitant to be critical but they did provide some points that had been less well received which included; use of jargon, delay in payments, travelling to workshops,

not having all the team at the workshop, and not all teams having a patient representative. Patient representatives welcomed the support and encouragement they were given and felt that their involvement helped the doctors to listen more carefully.

2.2.3 LIMBIC Illustration

The illustration was a visual impression of the LIMBIC project in a style which captured the story and illustrated the key features. A copy of the illustration is included in Appendix 8. Visually stimulating, the illustration offered a snap-shot of what the LIMBIC project was about. The inclusion of patient representatives in the illustration situated them within the body of the project as an integral part. The main way in which patient representatives were depicted in the illustration was in their role play during the film. Other key parts of the illustration were about objects such as the quality improvement tool-box and concepts such as the journey through the workshops. The illustration demonstrated the leading roles taken by the patient representatives in the film, whilst also capturing the key learning points of the project.

The illustration was an output of the LIMBIC project which reflected a moment in the LIMBIC story where the team and the participants had some fun whilst being creative. It had novelty value, but it also had impact on both the people involved and the people who observed the illustration as an output of the project.

D2.2.6 Conference posters and presentations

The patient representatives were keen to engage in these dissemination processes, and did so with enthusiasm and confidence. Those who gave presentations were motivated and willing and did so with confidence and conviction. Their eagerness to get involved illustrated their commitment to the goals of the project and showed how barriers had been removed, power had been transferred and the patient representatives were in control of telling the LIMBIC story.

D2.2.7 Papers and publications

The analysis of these data verified much of the earlier data. Much of the content pointed to a theme about patients taking control. Writing their stories exhibited their deep understanding of the project, their commitment, their improved confidence, their desire to give something back and their subsequent empowerment.

D2.2.8 Advising commissioners

The patient representatives demonstrated the confidence to engage in discussion with commissioners about improving services for patients in the future. The LIMBIC film continued to demonstrate its currency as it was used to introduce the event.

Summary of Stage Three

The analysis of the data from Stage Three of the study led to further clarification of the themes from the analysis of data from Stages One and Two of the study. Data saturation was reached during this stage of analysis. No further themes or codes were identified and many of the codes were verified. Some contradictions helped place appropriate codes to appropriate data. There were many opportunities for triangulation of data through verifying findings from one source with findings from another. The next stage was to bring together the findings from all three stages of the study to then explore the way in which these findings had addressed the research question.

4.4 Integration of the data from the three stages of the study

At this point, codes had been allocated to all the study data. Some themes were becoming apparent. Each unit of meaning was now coded, all codes had been assigned. All the coded data were then grouped under one of the new codes that had been created. No new codes were added at this stage although some renaming of codes and merging of codes had taken place in earlier stages of the analysis.

This study began with an overview of what was already known about service user involvement at the time and some further evidence which emerged as the study progressed has also been discussed. The analysis had begun to show themes which came from the data from the study participants about their service user experience. To help in synthesising these strands of current knowledge and new knowledge and to illustrate how the contextual factors of this research linked with the mechanisms that would lead to the outcomes, these features were drawn together in a list of prior research evidence from the literature. This was set alongside a list of these findings which described the service user experience in this study and the themes from the analysis of this study emerged. This process of data reduction and creation of themes is represented in Figure 19.

What is already known	Service user experience	Themes
Poor reporting	Lost opportunities, regret	**A feeling of togetherness**
Unclear purpose	Onlooker to expert	Unique learning experience
Difficult to find in the literature	Equal, power sharing	Community with an identity
Levels of involvement	Feeling valued	Being mirrors for one another; new
Principles for involvement	Unmet expectation	perspectives through diverse stories
Hierarchy or continuum	Unrealistic expectation	Transition to a new role
Impact of involvement difficult to	Productive learning environment	
evaluate	Feeling secure in the environment	**It's the way you tell 'em**
Changes researchers' attitudes to	Shared goals, shared journey	Communication through language
involvement	Shared learning	• the language of health
No clear impact on services	Influencing change	professionals
Breaks down barriers	Choice of levels of involvement	• the language of patients
Sharing experiences	No hierarchy, support	• communicating expectation
Equal partnerships	Respect	Sharing memories and experiences
Service user empowerment	Working together in partnership	No time to listen
Turn something negative into	Emotion	
something positive	Focus on the goals of the project	**Really wanting to make change**
Time constraints	Changed relationship	A renewed understanding
Power sharing	Desire to help others	A shift in attitudes, beliefs and
Support and training	Change in attitude and behaviour	perceptions
Seeing a different perspective	They saw the impact of involvement as	A shift in behaviour
Partnership	they saw change happen	The nature of the shift in the balance
	Taking the lead	of power

Figure 19. Data reduction process and thematic analysis

These factors which illustrated the co-learner experience showed that there were two important overarching concepts about service user involvement in this context. These were about the importance of preparation for service users in their co-learning role and secondly, the concept of working in partnership.

The overall analysis now led to the development of three major themes, illustrated in Figure 20. The themes developed over the course of a data analysis process which lasted some two years and which integrated groups of findings from the three stages of data analysis that have been outlined in this chapter. The themes began to develop as the analysis of the semi-structured interview transcripts began and then through processes of further data analysis, integration of reduced data from other sources and through verification and triangulation until the themes were seen.
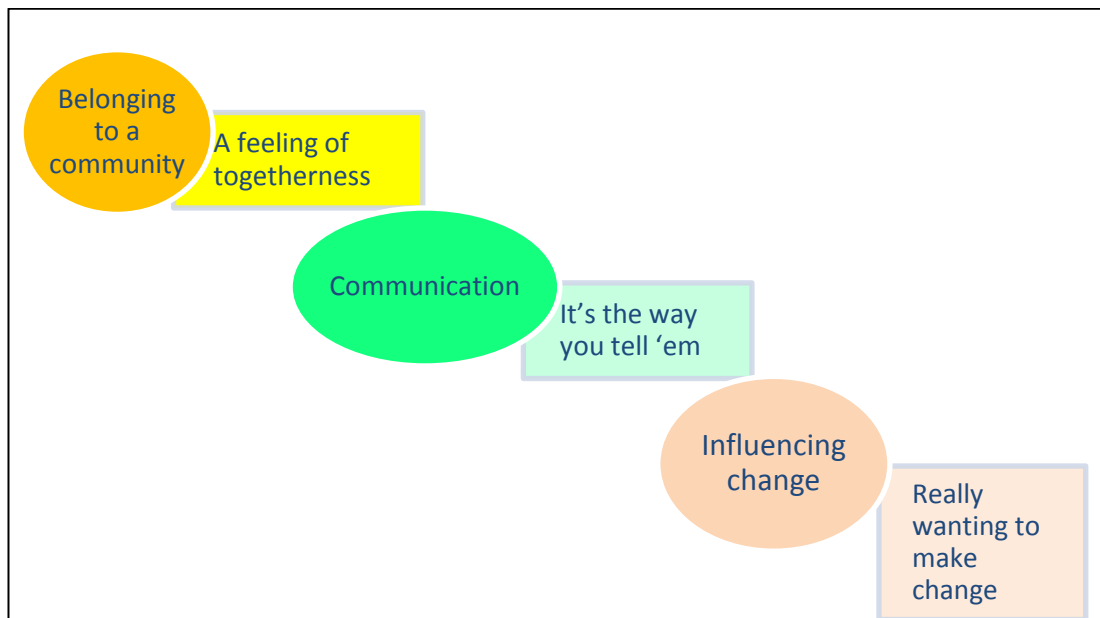
Figure 20. Three major themes

The three main themes developed through the analysis reflected the experiences of the patient representatives and their pleasure and surprise about being valued for their contribution to the research process. Themes were named using the language of the research participants. The first of the themes was about belonging to a community and is described using the words of one of the patient representatives as 'a feeling of togetherness' (Pam; Interview). The second theme related to communication and is described by using the words of one of the participants as 'it's

the way you tell 'em.' Influencing change emerged as the third major theme. 'Really wanting to make change' reflects on the patient representatives' reasons for joining the LIMBIC project and it also illustrates some of what they achieved, using the words used by one of them at the outset of the project "I really wanted to make change" (Stuart; Interview). The naming of the themes has been adjusted and altered through refining of the analysis processes and finalised as outlined in the three major themes, each with three or four sub-themes which represent the findings of the study in Figure 21.

A feeling of togetherness

| A unique learning experience | A community with an identity | Being mirrors for one another: new perspectives through diverse stories | Transition to a new role |

It's the way you tell 'em

| Communication through language | Sharing memories and experiences | No time to listen |

Really wanting to make change

| A renewed understanding | A shift in attitudes, beliefs and perceptions | A shift in behaviour | The nature of the shift in the balance of power |

Figure 21. Themes and sub-themes from the data analysis

The study findings will next be presented in relation to three main themes; 'a feeling of togetherness, 'it's the way you tell 'em' and 'really wanting to make change.' As I provide my interpretation of the research themes, I explore what these findings might represent and suggest insight into their meaning. I provide examples of narrative from the participants of the research project from a variety of sources, including the interviews that were undertaken. Upon giving a narrative example, a pseudonym is used for the individual participant alongside the source of the narrative sample.

Caution has been necessary to preserve the anonymity of the participants of the study, for example, where some of the events related to the LIMBIC project had only one patient representative involved, such as some of the conference presentations, one of the films, and some of the views expressed. Where patient representatives' quotations would make it possible to identify which individual was involved, there is no reference to the individual or the source material provided. Doing so might have made it possible to identify the research participant or cross referencing to other citations might have allowed this. Therefore, in order to consistently preserve anonymity of all the research participants it has sometimes been necessary to sacrifice revealing the source of the evidence or the participant's pseudonym.

Findings about the experience of being a service user involved in research were situated within these themes along with illustrative examples of patients' experiences of engaging with the healthcare system. The three themes each subsumed a number of sub-themes. Each one is presented and discussed in the next three chapters.

5.   Findings, Theme 1: A feeling of togetherness

'A feeling of togetherness' captured the essence of belonging to a community with a distinct culture and within it, a culture of people with pain. This community used their memories, knowledge and experiences to describe their learning which brought new perspectives and captured the benefits and challenges of "being on the other side" (Janet - interview). This theme illustrates what user involvement can add to enhance research processes and interprofessional learning. People from the community were seen to evolve together into new roles with new powers. Whilst the 'feeling of togetherness' was shared among most of the patient representatives, it took time for this to evolve.

Four sub-themes made up the overall theme of 'a feeling of togetherness.' Most patient representatives agreed that what they experienced together in their engagement with the LIMBIC project was a learning experience that they had not experienced before ('a unique learning experience') through which they shared their learning alongside healthcare professionals. Over the course of the workshops, some of the patient representatives formed relationships of trust and friendship for some. For all of them, being able to share their experience of living with back pain led to them feeling they belonged to a community of people with back pain ('a community with an identity'). Sharing their experiences and learning together led to the patient representatives looking differently at each other and at themselves ('being mirrors for one another: new perspectives through diverse stories'). The patient representatives started their engagement in the project in the role of patient but as they learned and as they began to see their potential to be able to change things many of them moved into roles similar to that of teacher or leader ('transition to a new role'). These sub-themes are illustrated in Figure 22.
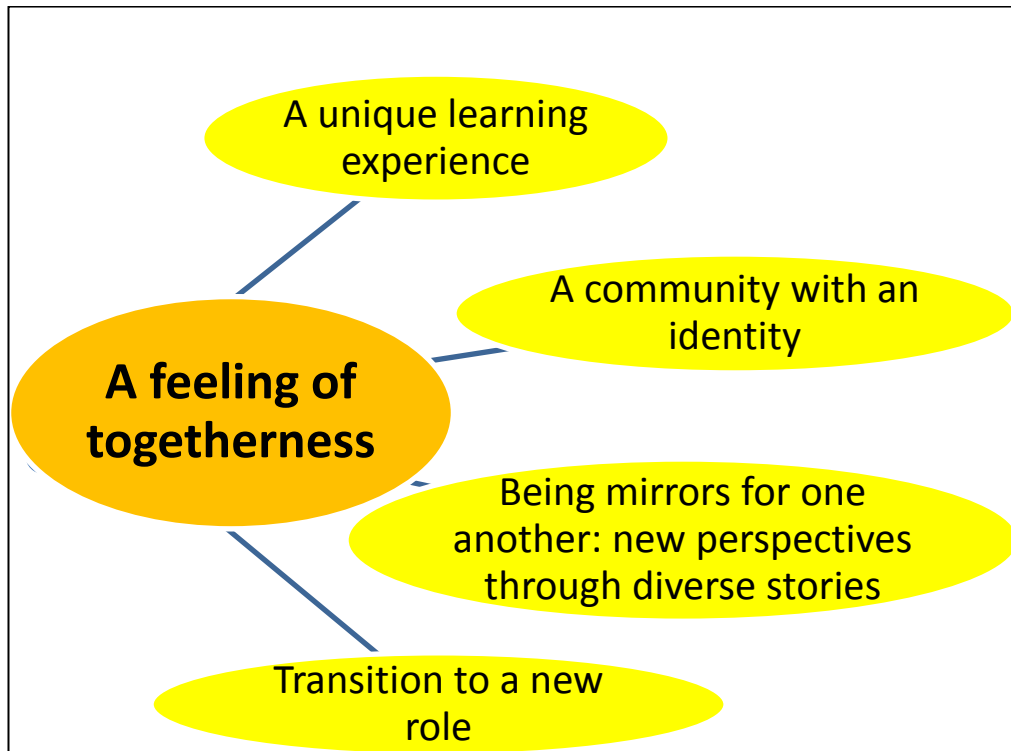
Figure 22. Sub-themes for 'a feeling of togetherness'

In a complex and uneven narrative, 'a feeling of togetherness' contained broken boundaries, new friendships, shared experiences, abandoned beliefs and mutual respect. Patient representatives welcomed the chance to talk to others who understood what it was like to live with chronic pain and their engagement in the LIMBIC project provided the opportunity to share a learning experience together in an unfamiliar but non-hierarchical learning environment.

Features of 'a feeling of togetherness' were familiar concepts about learning, sharing, co-constructing and being on a journey together. Participants shared stories about their experiences with each other; they shared a learning experience together which led them to build renewed ways of thinking about old ways of working. Their learning experience was a journey of discovery about what was already known about back pain and quality improvement and building a new framework together to support the teaching of their work. Their experience contained expressions of regret and for some the new learning which occurred was

particularly difficult to digest. There was also a transition from passive learner to expert teacher.

5.1   A unique learning experience

Apprehensive to start, most of the patient representatives wondered what was expected of them, feeling somewhat inadequate by expressing an awareness that the health care professionals were: "bright and intelligent people" (Christine; Interview). Later, they described the transition in their relationship with the members of their primary health care team from health care recipient to co-learner:

> "Instead of going up to the reception desk at the surgery and being there, it was almost as if you were taken round the back and becoming part of behind the scenes."

> Martin; Interview

Martin discovered a new world as he learned about the workings of a practice. "Behind the scenes" (Martin; Interview) suggests he was exposed to a new, possibly unique, experience with an almost theatrical tone. Before joining the project the patient representatives had viewed the practice environment as unknown territory, feeling alienated in their encounters with the practice team. To start, the patient representatives were "onlookers" (Lynne; Interview). Over time, a relationship developed where trust and understanding flourished and, as the project progressed, the patient representatives observed how the practice teams were learning and how they, the patient representatives, were influencing that process:

> "It was clear that it was a learning experience for many of the healthcare professionals there about looking at the patient holistically, and as an onlooker it was clear that there was an intent there to make healthcare professionals examine their interviews with patients, how they saw patients, were they taking an holistic approach, what messages were they giving patients, were they able to listen to patients?"

> Lynn; Interview

The practice teams observed how the patient representatives also learnt from their engagement with the project. One practice team which did not manage to recruit its own patient representative reflected upon this as:

> [A] "missed opportunity, [we] felt that other patients [patient representatives] have benefitted enormously from understanding how the system works and doesn't work."

> a LIMBIC practice; presentation at celebratory event

Patient representatives quickly understood that the purpose of the project was to facilitate learning by getting practice teams to work together on quality improvement projects and that working together collaboratively could enhance their learning:

> "I think in terms of their having contact with other practices and learning from other practices, I think that was a very valid learning experience for them [practice teams]."

> Lynn; Interview

Over time, the patient representatives were able to articulate how they understood the principles underpinning the LIMBIC project and their engagement became a feature of the success of the practice improvement projects and of the project as a whole. Patient representatives were pleased to see the changes they had suggested being implemented in practice, such as using the TV screen in the surgery waiting room to convey messages about back pain:

> "and to have that implemented [on the TV screen] within a week, and to know that the people that I was engaged with were taking that on board, that for me made it a truly 360 degree event and that suggests to me that's the whole thing working, in that they [the practice teams] were learning also. The doctors were all saying they were learning a great deal from the sessions."
> Stuart; Interview

The experience of learning together with health care professionals was new for the patient representatives which they described in many different ways as they observed that both they and practice teams were all learning. It had become a

shared experience. It became a changed relationship. Most of the patient representatives felt they were listened to, they were able to talk to the practice teams in the workshops, offer their opinions and have their views acted upon and they welcomed the fact that people were interested in what they had to say. "Being on the other side" (Jane; Interview) and "behind the scenes" (Martin; Interview) reflect the patient representatives' expressions about how they felt that they were in a privileged place. They felt proud to be able to help and were pleased to be asked to do so.

Many patient representatives valued the support that was put in place to help them in their role and this enhanced their involvement experience, for example, the setting of boundaries by agreeing ground rules at the outset of the project. Rules included avoiding the use of medical jargon and this contributed towards a better understanding of the workshop content for the patient representatives. It became a two-way exchange with all participants learning from each other. Other support which was provided included information packs, pre-workshop meetings for patient representatives, and access to the project wiki. In reflecting upon the workshops, one patient representative highlighted "the importance of the patient getting good information at the start" as the single best thing about the project (patient representative; workshop reflections).

Reviewing the meeting notes from the patient representative pre-workshop meetings colours the picture of the learning experience and shows how much they valued the sessions.

> "The pre-workshop sessions provided good opportunities to identify issues for further discussion and reflecting on previous learning so that they could go into the next workshop and gain further knowledge as well as contribute effectively. The sessions helped them gain a better understanding of the project, the role of the practice teams and the role of the patient representatives in participating in the improvement work."

> Researcher's review of pre-workshop meeting notes June 2011

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Patient representatives were gave their feedback about the workshops using a variety of words to describe their experience, a sample of which is illustrated in Figure 23.

Positive
enlightening
illuminating
It made me feel fabulous
empowering
It made me feel proud
a worthwhile, valuable experience
enjoyable
Too technical
disappointing
fun
eye-opening
exceptional
opened my eyes
stimulating
educational
useful
It was refreshing to see that they were all learning together, learning new things
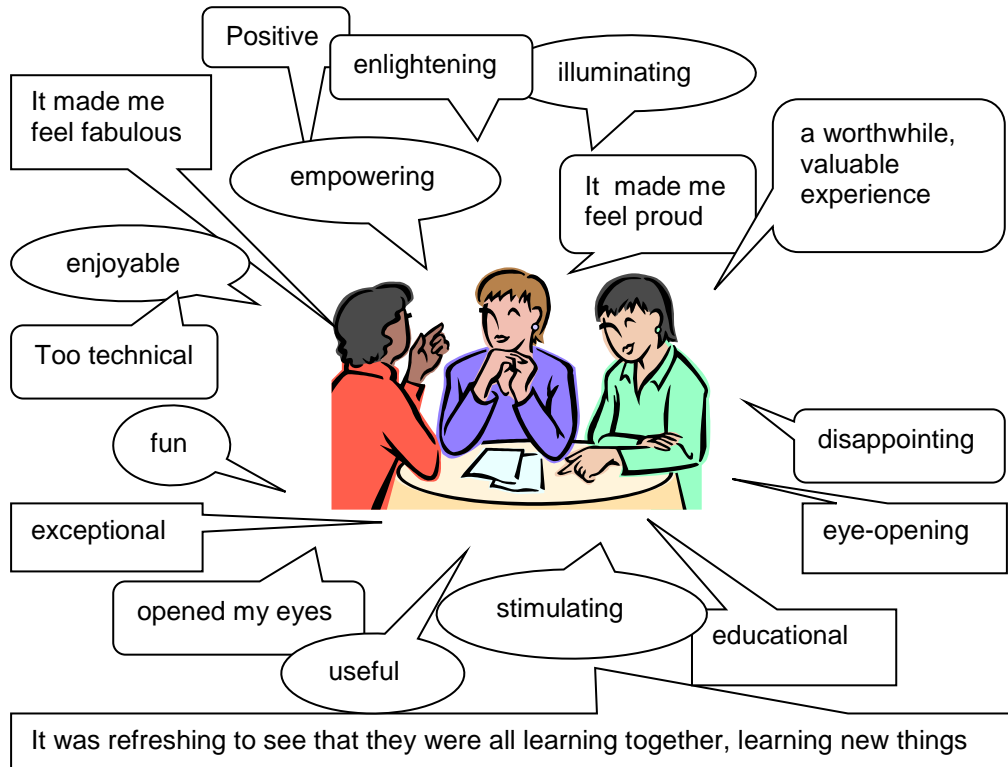
Figure 23. Words used to describe the experience of being involved

Most of the patient representatives engaged continuously throughout the series of workshops whereas the practice teams did not, their attendance was sometimes sporadic. Those patient representatives who had not been involved from the start, or who were not able to attend all the sessions, expressed regret about this:

"I sort of came in and it was like being the new boy in the middle of term. 'Oh, here's', you know, and 'you sit at that table', sort of thing [smiling] 'and this person will look after you and show you where the toilets are'. So it was a bit like that and that's possibly one of my regrets, that I wasn't involved at the beginning, because I would have had a chance to give my story and that would have been better, a better starting point."

Patient representative; Interview

This participant regretted joining the project late in the series of workshops because he had not had the opportunity to share his experiences with the group. Telling his story might have led to a different experience. It might have created a different 'unique learning experience.' Another patient representative who joined the project late described their arrival as, "I was parachuted in" (Patient representative; Interview).

Late joiners had reason to feel compromised. Upon joining the project at Workshop Four, they had missed a lot of the content and the learning and some team building activities. But this did not impact on their level of interest in the project or upon their continued engagement. Another patient representative who had joined the project late echoed Lynn's feeling of being an "onlooker" by describing how it took some time before they belonged to the group:

> "I felt that really in some ways, until I'd been to a number of these [workshops] you felt on the outside looking in."

> Patient representative: Post workshop focus group

Other patient representatives mirrored expressions of regret:

> "I was just really sorry that I wasn't able to make all of the workshops and all the meetings, and that is purely because I work full time."

> Patient representative; post workshop focus group

Expressions of regret also were made about the restricted potential to engage in the practice improvement work:

> "Sometimes if you were not part of a LIMBIC practice you were not able to be involved."

> Patient representative; workshop reflections

In describing their experience of engagement in the project, some patient representatives had difficulties. One found the improvement work difficult to grasp:

> "then if we were all together it might have been working on sort of the process map which is quite difficult as I've explained from a patient point of view to be too involved with, because we don't understand how the practice, the route the practice uses to sort their patients out."

<div align="right">Bob; Interview</div>

His lack of understanding did not prevent Bob's suggestions for improvement from being implemented in the practice (referenced later to preserve anonymity). Another patient representative did not like the pace of the workshops.

> "As a patient representative when you're at the meeting, you're trying to take in what you know hardly anything about, so you're concentrating on trying to keep up with the pace and so your thoughts are taken over by that and so you're not using your own thoughts too much, if that follows."

<div align="right">Andrea; Interview</div>

She also had expectations about how the workshops were delivered.

> "I wanted to stand up there and say 'Look, we're here for a reason, to start managing things a bit better'. I did feel a bit angry inside, that we were all sat there and you know we were having speaker after speaker of different things which is great, but we're not actually getting to the fine tuning of how these GPs and consultants can manage people's pain better."

<div align="right">Andrea; Interview</div>

She had a different understanding about the approach being taken in the workshops which aimed to initiate a series of small scale improvements that would influence GPs' management of people with back pain. Her understanding of what to expect was not therefore realistic as she had expected to observe the impact of her influence directly on clinical practice as a result of attending the workshops. This

shows how the expectations of individual patient representatives differed. Another patient representative observed:

> "Some of the patient representatives were there in the project because they were dissatisfied with the service they had been provided for their back pain."

<div align="center">Patient representative; post workshop focus group</div>

For those with unmet expectations, they had different interpretations of the principle aims of the project, either because they did not gain a detailed enough overview of the project beforehand, or their expectation for change had been unrealistic, or they were impatient. They might have wanted to learn more about managing their own back pain; they might have wanted to tell GPs about how they should be advising people about how to manage back pain. A mutual understanding about expectations of the role of the patient representative is necessary so that patients can engage, feel involved and contribute to the project.

In contrast, other patient representatives had a clear understanding as shown in a comment about some of the posters and story boards:

> "It showed that an awful lot of learning processes had gone on. That was evidence of learning in a big way."

<div align="center">Martin; Interview</div>

Some patient representatives made suggestions about how the workshops could have been improved:

> "I think it was slow to get going. The first couple of workshops I felt, I know we covered quite a lot of work but I wasn't quite sure what we got out of this. So I think perhaps if it was run again, just providing how to kick start them."

<div align="center">Lynn; Post workshop focus group</div>

> "Cut it out [presentations] and add more role play and more interaction and that would have been better from my point of view."
>
> Kevin; Post workshop focus group

These suggestions show how the patient representatives wanted to use their experience to influence future similar activities.

There was some uncomfortable learning. Patient representatives learnt that there was usually no cure for chronic back pain, that it was a long term condition requiring continuous self-management. Some already knew this and the learning from the workshops confirmed it:

> "At the end of my contribution to the LIMBIC project I realised I had learnt two important lessons. Firstly that everyone's experience of back pain is different and sometimes there is no magic bullet, sometimes, and this may be difficult for some patients to accept, there is no cure. Secondly, that to deal with back pain effectively, a partnership is required between the practice and the patient."
>
> Patient representative; Article in BackCare members' bulletin

The 'unique learning experience' which contributed to the 'feeling of togetherness' illustrated how patient representatives began to understand how practices worked and they saw a new world open up to them as they became part of what went on behind the scenes in general practice. Most of the patient representatives welcomed this new learning but some did not understand and did not see it as relevant to them. The patient representatives moved from an apprehensive start to becoming members of functioning learning teams, willing to put forward their suggestions and working towards shared goals with their practice collaborators. Part of the unique learning experience involved patient representatives coming together as a community and this is discussed in the next theme: 'a community with an identity'.

My reflection

The fact that the learning experience felt unique could have influenced the patient representatives' decisions to give an interview about their experience. The learning component of the unique experience was evident across all participants which might have influenced their continued engagement with the project. The practice teams also had a unique learning experience because their learning took place in a setting with patients as co-learners and some practices provided feedback suggesting this could be so. The 'feeling of togetherness' was portrayed across all the patient representatives. It was not dependent upon how much they engaged in the project. Those who gave a critical perspective were equally part of the togetherness which formed the co-learning community for the project to evolve. The strength of the need to tell their stories was a telling feature of this theme and goes some way to understanding their experience of involvement.

Patient representatives were surprised to see the practice teams learning; evident in their observations and descriptions of changes being made in practice. None of the patient representatives had previous experience of co-learning with practice teams. Their surprise could be because it was a new experience for them or because they did not expect to see the practice teams learn or they thought the practice teams should already know the basic principles about managing back pain and quality improvement. Those who said the workshops had not achieved very much might have felt that way because they themselves were aware that back pain needs a self-management approach and so this was not a new piece of learning for them.

Learning about the patient perspective

In trying to understand the experience of involvement from the patient perspective, I have learned that many of the patient representatives fully understood the principles of the project and this clearly influenced their experience. The support made available to them at the commencement of the project influenced this and contributed to their feeling valued. The experience was new to them all, and new to the practice teams; none of them had engaged in similar projects before and this novelty aspect of the project probably made them feel more secure in the knowledge that all the participants were doing something new together. For most,

their starting point was that of onlooker and this was to change over the course of their engagement. The environment, likened to 'behind the scenes' in a theatre, was also new and it was a neutral environment, new to all of the participants and this is relevant to the development of the co-learning relationship which evolved. Patient representatives demonstrated emotional attachment to the project in their expressions of regret about things they were unable to do and in spite of this they provided useful suggestions for improvement in future projects. There were lost opportunities for some patient representatives that might have been possible to avoid. Joining the project late, not belonging to a LIMBIC practice, not being able to fully participate in all of the improvement learning and not fully understanding the principles of the project were all situations which if addressed at the time, might have been able to prevent the unrealistic expectations that were held by some of the patient representatives. The commitment to influence improvements for the future was a major feature of their experience for most of the patient representatives.

5.2   A community with an identity

The patient representatives established their common values through the shared learning experience, leading gradually to the embodiment of a community. They embraced their responsibilities with enthusiasm and co-operated well together. They conversed openly in their group meetings, both with practice teams and with fellow patient representatives and the heterogeneity of the group felt important to them:

> "So it was a good idea that there were a number of different people with different attitudes and different ideas there which actually were more of a catalyst."

Kevin; Interview

Although some of the patient representatives had their differences, they still managed to make a contribution as a group and individually. They talked about how they were treated with integrity and respect, they were treated as equals, they were listened to and they described how their input to the project was valued:

"I think we were always made to feel welcome, I think our input as patient representatives was valued, and not only was it valued, but we were told it was valued, so that was, it was explicit that what we had to offer would be valued."

<div align="right">Lynn; Interview</div>

"Everyone respected and appreciated what everyone else was doing."

<div align="right">Christine; Interview</div>

"Yes it was equal partners. Well it was equal all the way through wasn't it?"

<div align="right">Pam; Interview</div>

The value of having a patient representative on their team was shown by one of the practice teams who demonstrated their delight at recruiting their patient representative by posting a welcome message on their wiki page:

"We are all delighted to welcome [name] as our patient representative, his input has already proved valuable."

<div align="right">Practice I; project wiki posting</div>

Patient representatives approached the project with open minds and seemed to be surprised that the practice teams were similarly open-minded within the workshop discussions. This approach was inclusive and it made the patient representatives feel involved. There was an informality that allowed people to engage:

"I felt we were all on equal terms if you understand what I mean by that, equal terms and people as people who were all working towards the same goal."

<div align="right">Christine; Interview</div>

The feeling of being equal as a new concept is a contributory factor of the patient experience suggesting that patient representatives might not have expected to feel equal before they entered the project. They did not usually have the feeling of being

equal when they were in the role of a person seeking health advice. Part of the learning process was about a changed dynamic in the relationship between the health care professional and the patient to one where equality and respect were evident. Respect for patient representatives was shown in the setting of ground rules by the project team. One patient representative recollected her GP saying it was "great to have her on the project" (Patient representative; Post workshop focus group). Another patient described her surprise at the inclusive approach towards the patient representatives:

> "I think that one of the things that has struck me was the inclusivity really. As the patient rep and very much the lay person I approached the project thinking, 'well, I'm not quite sure how this is going to work.' I found all the time throughout any of the workshops that patients' viewpoints were valued and thought that was really nice."

> Lynn; post workshop focus group

Describing their community, the patient representatives said they enjoyed meeting people, learning new things and being able to see things from a different perspective. In this environment their sense of togetherness flourished:

> "It was a truly shared experience with an intelligent group of people which was quite stimulating frankly. It was good."

> Stuart; Interview

Not all the patient representatives managed to meet each other; there was never an occasion when they were all together, and some regretted this potentially lost opportunity:

> "I didn't meet all of them at once, and some of them I never met, I don't think, ships in the night."

> Patient representative; Interview

Wanting to help others was a motivating factor for many of the patient representatives in their desire to engage with the project and they found that helping

others was rewarding. They wanted to influence changes in order to improve the experience for others in the future:

> "But to have been part of it made me feel as if I was putting a bit of myself to it because with the health service there are times it has looked after me and it will do in the future so it was nice to give something back."

> Stuart; Interview

Patient representatives fully understood that the ultimate goal of the whole project was to improve the experience for patients with back pain:

> "I found it very rewarding and to have the understanding that in the future that could be impacted nationally, could resolve what previously for me was almost an endless cycle of referral and referral and referral with no end in sight, that would be very fulfilling for me personally."

> Patient representative; LIMBIC film

Although patient representatives shared similar hopes for patients in future, not all of them believed that this was achieved:

> "I was hoping that it would be of benefit to other people because having suffered for many years with a bad back, you would quite like other people to benefit from any knowledge and I don't think that happened."

> Bob; Interview

It appeared that Bob wanted to see immediate results from the project and this is similar to Andrea's earlier comment about wanting to "get to the fine tuning of what it's like for people with back pain."

Although written and verbal information about the goals of the project and what they could expect from their engagement in the project were made available to patient representatives at the start, there was no process undertaken for checking whether they had read this information. The patient representatives' meetings on the morning of each workshop provided the opportunity to seek how this information was interpreted by each of the patient representatives, but not all of them attended

these meetings. Their hope to see immediate impact of the project, although extremely valid was probably unrealistic given the project aims. For those who expected to see immediate impact, their expectations could have occurred as a result of them not receiving, or accessing the right information at the time they were recruited to the project.

There was no sense of a hierarchy within the project. Patient representatives found everyone to be approachable and felt they were treated equally. They described other participants as being "like colleagues" (Stuart; Interview). The non-hierarchical aspect was about patient representatives being respected for what they knew, as well as health care professionals being respected for their knowledge.

Towards the end of the project the patient representatives saw that the practice teams were taking back pain seriously when they began to listen to patients. It surprised one patient representative when he saw that GPs cared about patients and that they had compassion:

> "The GPs and healthcare professionals that were there obviously were taking on board how important and how people felt, how patients did get help. That did come through. As I said earlier they did care."

> Martin; Interview

The identity of the patient group within the setting of the project was around mutual trust and equality, caring for one another and wanting to help others. This was exhibited through behaviour, language and a shared learning. The formation of an identity allowed the group to develop behaviours which complemented their reasons for being there. They were able to learn about each other and from each other, and see things from a new perspective.

My reflection
The UK health care system has a distinct culture; people behave in set ways, they speak using jargon, they have expectations and their behaviours are predictable as a consequence of that culture. It could be that the patient representatives mimicked

this behaviour by forming their own community and culture in order to develop themselves into a body with a voice which could be heard. They knew their own individual strengths and recognised the value of joining together as a group to form a collective voice in their very own discipline, like a "community of practice" (Wenger 1998). Most of them put aside their differences. The patient representative community shared some of their behaviours and experiences with the health care community so they had a common understanding, and the health care community shared their language and their explanations of their processes and practices with the patient representatives. As a result, all those involved were provided with the opportunity to gain new perspectives, following the co-creation of an environment for discussion with each person bringing their particular expertise.

For the patient representatives who did not feel that there was much change, they expected to see changes in practice early on. They had not connected in the same way because their expectations of being in the workshops were not clear to them.

Learning about the patient perspective
In trying to understand the experience of involvement from the patient perspective, the strong sense of respect and valuing each other's perspective was a key finding in illustrating the identity of the community. The lack of hierarchy and agreement of ground rules assisted in the development of relationships which produced outcomes for the project team and patients. Receiving information about the long term nature of their chronic condition did not seem to deter the patient representatives from engaging fully in the project and they seemed to benefit from knowing that their work might contribute towards helping others in the future. Being made to feel equal and being told they were valued were important aspects of the patient experience in the context of this project. There was, however, also a sense for some of unmet expectation and failing to see any benefits for people with back pain as a result of the project.

5.3   Being mirrors for one another: new perspectives through diverse stories

The patient representatives were able gain insight into the lives, experiences and perspectives of others. Sharing their experiences enabled them to see themselves and others in different ways. One patient representative observed health care professionals taking an interest in people with back pain:

> "My feeling when I was at the workshop was that colleagues who were in the medical profession were interested in working on this, their level of professionalism and wanting to improve back care for patients was very reassuring for someone who is a back pain sufferer."
>
> Lynn; post workshop focus group

Patient representatives came into the project from a different place to that of the practice teams, both in their views and in their place in society, as they perceived it. Engagement in the project enabled them to cross a line. During the course of the project they had "crossed the boundary of the receptionist sliding glass door" (Martin; Interview). Once behind the door they needed to understand what life was like, what the culture was like, what language was used and how to engage with the people there. Having developed their 'community with an identity' and then gaining insight by being immersed in the culture of the NHS, they soon began to see the benefits of seeing things in a different light:

> "I thought it was very illuminating to see it from the GPs' point of view and from the healthcare professionals'."
>
> Lynn; Interview

> "Hearing the [other] patient representatives' journeys helped me put mine in a different perspective."
>
> Patient representative story; practice story board

With their new perspective they were able to offer helpful input to the project in a number of different ways, but they differed in their participation with some being

more interested in engaging with their peers and others more at ease engaging with the healthcare professionals:

> "I wouldn't say that meeting other back pain sufferers was necessarily a positive thing for myself."

<div align="right">Stuart; Interview</div>

Articulated in Stuart's comment, patient representatives felt different from each other and from the practice teams and some described feelings of inadequacy:

> "Yes I felt because everyone was going to be so intelligent and so bright I just thought I wondered how long I would last and I'm just delighted that I've stayed until now."

<div align="right">Christine; Interview</div>

Christine's comment links to the concept of there being no sense of hierarchy in the workshops facilitating an environment where learning could flourish because participants felt at ease with one another. There were tensions though. Difficulties were reported by patient representatives about their participation in the workshops, for example, not enough time in the workshops and not having the time to attend all of the workshops or practice meetings, which they regretted and some of them wanted more structure to the meetings:

> "I would have quite liked some kind of agenda so that I could think beforehand about the issues because I'm somebody who likes to reflect and come having done some thinking."

<div align="right">Lynn; Interview</div>

Tensions were observed in the patient representative group sessions. One individual was thought to dominate some of the discussions:

> "I strongly felt that it was particularly dominated by one of the patient representatives [who] dominated the time and gave little time for others to express their views, in fact for me I don't suffer fools, but I tried to be very patient."

<div align="right">Patient representative; Interview</div>

One patient representative who saw the project as a lost opportunity suggested they were probably not the right sort of person:

> "I think with the LIMBIC project possibly I wasn't the best person to act as a patient representative because I tend not to integrate too well anyway. I'm quite happy with myself which, that's got to be taken into account [pause] describing the project I think it was a bit of a lost opportunity."

> Patient representative; Interview

It appears they saw that patient representatives were required to interact with one another reflecting that they are not the sort of person who mixes well with others. They may be reflecting that the lost opportunity was theirs, in that they did not engage much with the other patient representatives, or they may be suggesting that the project was structured in a way that prevented them from engaging in a way which suited them. Alternatively, it may have been a lost opportunity from the health care professionals' perspective in that they did not gain what this person had to offer because of how the project was structured. This is important to note in describing the patient experience of involvement. Different experiences could be influenced by the degree of clarity around expectation or about recruitment processes for each of the individual patient representatives. It may reflect the fact that certain people are just not suited to undertaking a service user involvement role. A key learning point from this is that teams which engage with patients in involvement roles need to apply time and effort to the recruitment of patients and they need to be prepared for mistakes to occur.

For most of the patient representatives it was important to them to be able to relate to one another and so they needed to find things they had in common. In addition to their experiences of chronic back pain the majority of the patient representatives did find common ground.

The people participating in the project recognised that they were different in the ways they viewed the world and in the ways they communicated with one another. Where differences were apparent which could have had an impact on the discussions, participants put these differences to one side and worked together

towards a common goal; to influence change and to improve things for patients in the future.

My reflection

Patient representatives were not all immediately aware of their new perspective, that they were seeing things differently as a result of being engaged in the project. Whilst not all were aware at the time, they realised towards the end of the project, or afterwards, that they had been given the support they needed to develop their collective role and by seeing things in new ways they were able to confidently engage at a level which utilised their learning as well as their experience. It was apparent to me, not immediately, but towards the end of the workshops that their influence on the project was central to the improvement work and to the learning experience of the practice teams. They had adopted a deep approach to their learning and had come to recognise and replace their preconceptions.

The differences between peoples' attitudes to the project, their engagement with the work of the project and in personal characteristics felt like a barrier to progress at times. Verbal differences were aired within meetings but in polite and jovial ways. There were frustrations about practices not always engaging but observing and experiencing differences of opinion had an effect upon each individual's approach to the project. Looking at others helped patient representatives look at themselves. Disagreements between individuals led them to question their understanding and sometimes take a new approach. Some of the descriptions which patient representatives gave about their experience reflected an unfulfilling experience but further exploration showed a self-reflective type of conversation which helped me to better understand their experience of engagement. Some patient representatives did not enjoy their involvement in the LIMBIC project but undertaking the research interview allowed them to explore this experience and showed that they did learn from the project even if they did not feel that they had gained anything. This adds to the evidence suggesting that their initial expectation might have been unrealistic.

Learning about the patient perspective

In trying to understand the experience of involvement from the patient perspective I have learned that clarity about expectations is a key contribution towards the patient

experience and this should include negotiations and discussions about the role. They should also have clear expectations of the role of the research team and their co-learner participants. Preparation for the role can help to ensure their readiness to accept differences and difficulties and to allow for mistakes. The support team can provide role model behaviour for the group. Features of the setting should include openness, acceptance of differences and willingness to listen. The support that a group can provide for its members can help to create a productive learning environment. Participants need to feel secure in the environment in order for them to engage in open and honest discussion with each other.

5.4   Transition to a new role

Behaviour change is required for implementing the changes associated with quality improvement. Exposure to new perspectives for the patient representatives led them to change their behaviour and they observed behaviour change in the practice teams. This led to a change in the role of the patient representatives in relation to the practice teams; from novice learner to confident participant with a deep understanding about their experiential knowledge around back pain. In their novice learner role, patient representatives saw their GPs as holding a different status to themselves, both socially and intellectually:

> "I thought that doctors were little gods and I thought they would probably take a long long time to come round to listening to what the patients were saying to them."

> Christine: Interview

> "They might be very intelligent but some patients look on doctors as being little gods."

> Christine: Interview

> "You are sitting in front of somebody who has got a vast amount of knowledge the brain the size of a planet and all of the rest of what goes on with that."

> Stuart: Interview

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The research team put in place an infrastructure that facilitated effective patient involvement in the LIMBIC project, allowing them to exploit the wealth of knowledge held by the patient representatives and they became less intimidated by the perceived difference in status between themselves and the GPs.

Role play was one of the approaches they used throughout the LIMBIC project which provided opportunities for creativity to flourish. During the workshop sessions role play exercises involved the research team depicting the typical clinical consultation for back pain. One patient representative found it frustrating that they were not asked to act out themselves as patients:

> "The role plays, although they were a little contrived, I would like them to have asked one of us to play the patient. I was willing [name] to say something else, you know, and I thought, 'Let us do this bit, we know what we want to say to a GP.'"

> Lynn; Interview

Assumptions were made by the research team that they were best placed to deliver the role play sessions. In the LIMBIC film patient representatives rose to the occasion when they were later given the opportunity of role play showing that they were confident and able to play the role of health care professionals. The aim of the film was to illustrate the learning that had taken place during the LIMBIC project. The role play scenarios at the beginning of the LIMBIC film demonstrated the GPs' usual approach to managing patients with back pain. The patient representatives re-lived their pain whilst the practice staff dramatised their lack of understanding and false sympathies in the first set of scenarios. Patient representatives portrayed GPs in this initial setting, before exposure to the workshops, to have an unsympathetic approach, as busy doctors with no time to talk to the patient about how they were feeling.

The excerpt in Figure 24 from the transcript of the LIMBIC film shows how patients perceived the GP consultation *prior to* their improvement learning in the workshops. Pseudonyms used in the excerpts have been changed from those used in the remainder of this thesis in order to preserve anonymity.

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Pat as GP	*Now then*
Annie as patient	[interrupts] *'scuse me'.*
Pat as GP	*Now let me just get you up on the screen* [laughter from the audience] *now what seems to be the trouble?* [looking at the screen, not looking at the patient, then turns to patient] *you don't know the cricket scores do you?* [patient struggling to sit in chair] *do you..?*
Annie as patient	[Interrupts] *Could you just distract yourself from your computer and look at me while I'm trying to explain* [almost crying]
Pat as GP	[hands prescription to patient without looking at her, tapping his finger on the desk with a sense of impatience] *Some paracetomol for you.*
Annie as patient	*Will you stop that tapping.*
Director	*And cut.*
Annie as herself	[smiles] *You're like a doctor.*

Figure 24. Excerpt One from film transcript

The patient representatives were confident to demonstrate their understanding of the role of the GP in the consultation about the management of back pain and they were willing to do so in the group setting of the filming session. In the scenario in Figure 24, patient representative Pat, in role as the GP, does not seem to care about the patient's pain or any other aspect of her life and this is shown by his failure to make any eye contact or take any medical details. In a final comment made after filming the scenario was finished, Annie, as herself, observed how realistically the role of the doctor, played by Pat, had been portrayed.

In the post-workshop scenarios, patient representatives displayed the change in behaviour, which occurred as a result of the workshops, when they played the role of the GP in the back pain consultation, showing sensitivity towards their patients' needs. Through this role play, patient representatives showed they had observed a shift in the GPs' attitudes towards patients with back pain and gained a better understanding about how to engage with their patients in the context of the clinical

consultation. The post workshop scenarios showed the best practice approach to managing back pain and were acted out by the patient representatives who characterised the GPs as caring, sympathetic, understanding, open and honest. The next excerpt shows how the patient representatives illustrated their understanding of the GPs' changed behaviour following their learning experience.

Marjorie as GP	*Annie, make an appointment with the receptionist and come back and see me again next week, so here's a leaflet.*
Annie as patient	*Thank you.*
Marjorie as GP	*And there's as I say there are those five exercises on there, now do them very gently, make time for yourself, and forget about your family.*
Annie as patient	*When?*
Marjorie as GP	*Well make time, you've got to make time otherwise*
Annie as patient	*It's all very well*
Marjorie as GP	*Otherwise you're never going to get better and if you don't look after yourself nobody else will. You must look after yourself.*

Figure 25. Excerpt Two from film transcript

In the excerpt in Figure 25, Marjorie, as the GP, is trying to show she understands that the appropriate care and treatment, which includes doing exercises, is difficult to fit into Annie's lifestyle when exercise is not part of her routine. Marjorie is trying to make sure that Annie makes an effort to focus attention on herself in order to improve her condition, therefore showing that she has understood the importance of considering the bio-psycho-social aspects of the patient's life. Compared to the excerpt in the earlier Figure 24, this example demonstrates an improved doctor-patient encounter; the GP is engaging in meaningful dialogue with the patient and is offering evidence based support and advice with a caring approach.

The way in which patient representatives confidently and willingly took on the role of GP, and showed how they had understood the learning which had taken place and its influence on the attitude and behaviour change in the GPs is a powerful example of their learning, their understanding and their commitment to the project aims. The

film became a tool to spread the learning from the project to wider audiences and the patient representatives were committed to this.

The process by which patient representatives engaged with the project, with each other and with the practice teams gave them the confidence to lead discussions about key aspects in the delivery of the LIMBIC project. They transferred to a new role in which they assumed more assertive behaviour and became involved in decision-making.

At another level, this part of the project, where patient representatives took lead roles, demonstrated their transition from a passive learner role, to co-learner within the workshops and then on to teacher through the medium of film. For those patient representatives who did make a transition, their expert teacher role was illustrated in several ways. They facilitated the spread of the learning from the LIMBIC project through workshops, a master class presentation, conference attendances, writing articles for a number of health-related bulletins and newsletters and through joining planning meetings with health service commissioners. A GP commissioner later reported:

> "The shared knowledge and experience that came from working as part of the LIMBIC team made the [commissioning] meeting easier to construct and easier for us to develop shared outcomes. I was particularly impressed with the input from the LIMBIC patients' group. They were able to understand the issues and contribute positively to the debate having the confidence and knowledge to put their views across effectively. They were also a valuable sounding board to make sure that our response to the [NICE] guidance was relevant to the needs of the local population. The lessons we have learnt about patient involvement, peer education and service development will remain with us."

> GP commissioning lead; LIMBIC project report

The transition made by some patient representatives was about leadership. They were confident to use their learning to show how they would like to be treated when they sought advice from their GP about their condition. But it was more than this. Patient representatives, along with the research team and the practice teams, had co-created a facilitative learning environment which they exploited by seizing the

opportunity to show others how their experience of engaging with the project had mirrored their experience of engaging with health services in seeking treatment for back pain, with the difference being that they were now in control, both of their condition and of their role in supporting the research team in delivering the messages of the project. The eagerness with which these patient representatives embraced their new role was described by one of them:

> "It was at my first meeting with other patient representatives that convinced me of the value of the LIMBIC project. We all had long term back problems and we had all received varying levels of care from our GPs and local health services. Here we all realised quickly was an opportunity to help to improve that treatment for other patients."

> Patient representative; BackCare members' bulletin

My reflection

The continuum of involvement (INVOLVE 2009) describes patients engaging at three possible levels; either as recipients or collaborators or in a consultative role when getting involved in research. I had not expected to observe patient representatives engaging in this variety of levels during the course of the LIMBIC project. Whilst the conditions were optimised for patient representatives to have the confidence to take control in parts of the research process there are several factors which led to this happening. The non-hierarchical co-learning relationship between patient representatives and health care professionals was an important factor. Features of this relationship included trust, honesty and shared commitment. The control was sometimes shared, sometimes in the hands of the research team or the practices and sometimes it was in the hands of the patient representatives. There were no rules about this. It happened as it needed to. There was a shared understanding which enabled this to happen, underpinned by trust, equality and shared goals which had grown over a shared journey.

Learning about the patient perspective

In trying to understand the experience of involvement from the patient perspective, their capacity for taking control cannot be under-estimated. Power can be handed to the patients if there are clear shared goals and there is a relationship of trust. Lost opportunities will occur if the wealth of expertise held by patient representatives is not fully recognised. Support teams need to prepare to give control to the patients if the opportunity arises. Patient representatives may surprise their health professional colleagues by their ability to influence change.

It is also important to maintain an awareness of people's preferences for engagement by placing effort into discussions about expectations at the outset of a project and the research team should be prepared to accept that different individuals will opt to engage at different levels.

5.5   Summary of Theme 1: A feeling of togetherness

The principles of 'a feeling of togetherness' are about the experiences of a group of people on a journey (Figure 26). The people were the patient representatives in a research project, the LIMBIC project, and the journey was a series of relationships which built over a period of time and which started out with apprehension and ended in respect, trust and honesty, but also some regret. The engagement with the LIMBIC project was a 'unique learning experience' in which participants shared their experiences of a debilitating long term condition, chronic back pain. Sharing experiences enabled the group to gain in confidence and show respect towards one another. Relationships developed where people learnt from each other and this enabled them to see things from new perspectives. By experiencing new perspectives, the patient representatives developed the confidence to exhibit their learning by assuming the role of expert, teacher and leader.
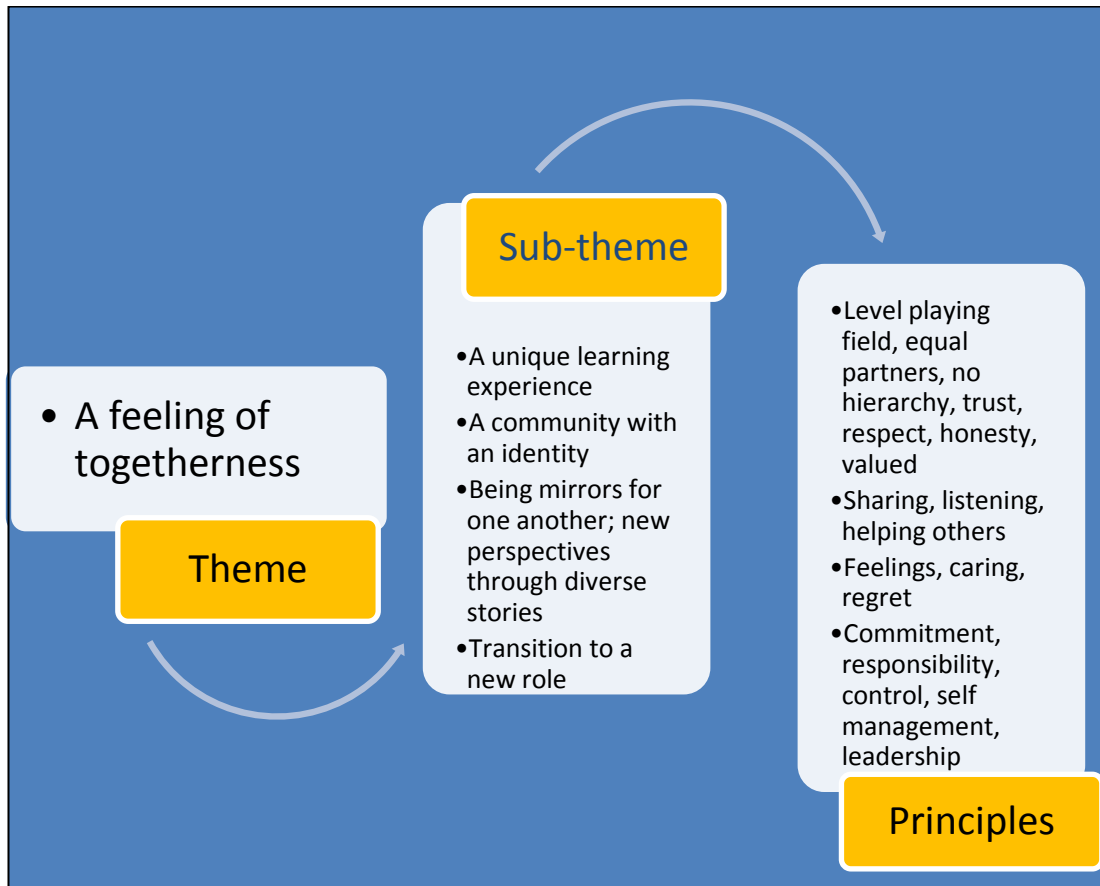
Figure 26. A feeling of togetherness - themes and principles

'A feeling of togetherness' sounds cosy, as if everything in the project was enjoyable and people got on together all the time, which they did not. The theme is describing the way in which all of the project participants shared a learning experience with a shared goal and it reflects what the patient representatives said about how it made them feel. Sometimes the learning was uncomfortable to hear about when the message said there is no cure. Participants expressed feelings of regret about lost opportunities and the different personalities held differing opinions.

The principles of sharing, trust, respect and honesty show how the processes which were undertaken through the research influenced behaviour change and attitudinal change. Another contributory factor to the learning experience was the language which was utilised by the different groups of people and this is explored further in the theme called 'It's the way you tell 'em'.

6.   Findings, Theme 2: It's the way you tell 'em

Whilst the 'feeling of togetherness' described the participants' journey through the LIMBIC project which followed a well prepared and continuously maintained path, 'it's the way you tell 'em' emphasised the value of their spoken words. This community of people engaged in the research found that they needed help with interpretation and explanation some of the time in order to understand the language.

The language we use is important when we communicate as well as in our encounters in the health setting. One patient representative tried to understand why GPs might struggle in communicating with patients about what their condition might mean to them:

> "'It's the way you tell 'em', to use an old expression, isn't it. And maybe GPs, practices, find it very difficult to tell people that, 'we've done all we can for you', you know, that's hard for a GP to say, isn't it? 'I'm sorry, we've done our best, you're on your own now'. I mean professionally as well as emotionally with the patient."
>
> Martin; Interview

This theme shows people trying to understand their use of language, how they choose their words and questioning whether they are careful enough about how they clarify the words of others and the messages given to others through language and behaviour. Illustrated in Figure 27, three sub-themes make up 'It's the way you tell 'em.'
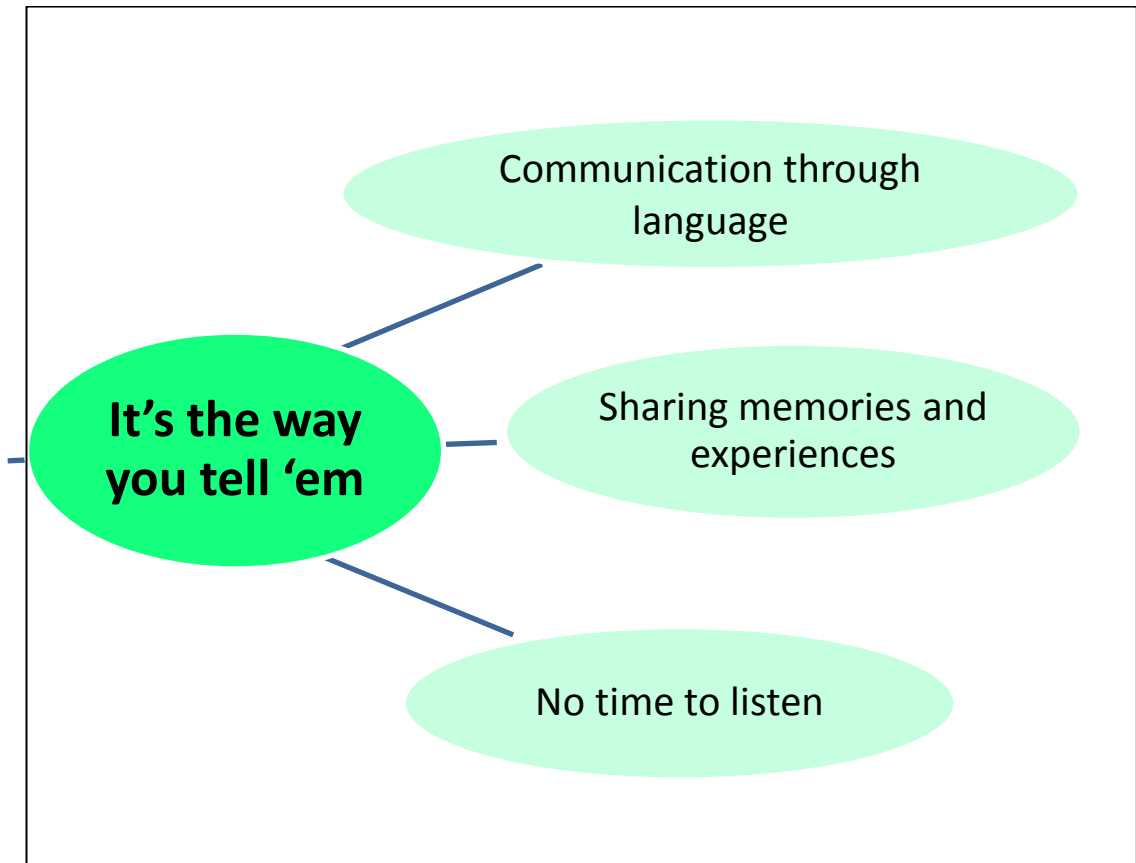
Figure 27. Sub themes for "It's the way you tell 'em"

'It's the way you tell 'em' illustrates the way in which people communicated with each other and the importance they attributed to listening and hearing. There was a language of health care professionals and another language for patient representatives and they had to work together to find a way that they could understand one another ('communication through language'). Once their language was agreed they all began to benefit by sharing their experiences in learning together ('sharing memories and experiences') and this included experiences of back pain and accessing health services. Running throughout the theme were expressions of expectation, emotion, and hope for a changed future. They had not been given the time they needed in their health care experiences to tell their story and be listened to ('no time to listen').

6.1 Communication through language

Communication inevitably arises as a challenge for those attempting to improve quality. In the LIMBIC project, the use of language and ability to communicate effectively emerged as a potential barrier from the perspective of patient representatives. Initially, when a common language was not being used, for example when jargon was used, this impacted on the patient experience, making them feel inadequate, whereas when a common language was used, it made a good starting point for effective communication. Choice of language therefore impacted on the patient representative experience. In the encounter between patient and health care professional there are challenges in creating a satisfactory patient experience and this study included stories of ineffective interactions with health care professionals. Recurring throughout this theme and across the study is the importance of communicating expectation. Firstly, we see how language can influence our interpretation of the messages of others.

6.1.1 The language of healthcare professionals

When patients are given explanations about their condition health care professionals may use terms which are not well understood by patients which can lead to misunderstandings. The patient representatives had different views about the chances of finding a cure for their condition. Despite this, they reached a consensus towards the end of the project that there was no cure for their condition. Patient representatives fully understood that they needed to manage their condition themselves and that it was unlikely that it would ever be completely cured. Some of them had not been told this explicitly; they had had to work this out for themselves. Health professionals had not effectively communicated the appropriate information to the patients who had chronic back pain:

> "I think a lot of doctors are completely straight but some doctors
> do struggle with it, being direct or having direct communication
> with people."

Stuart; Interview

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In describing their experiences of poor communication between health care professionals and themselves, patient representative said that when bad news was to be delivered the most important aspect was "who tells it and the way you tell it" (Martin; Interview).

They perceived healthcare professionals to lack empathy for people with back pain and they did not give patients enough time to talk about their condition:

> "I think the dialogue between the medical profession and patients is such a valuable one, and it really would be so useful to have much more interaction, much more involvement in things so that you can actually understand some of the issues."
>
> Patient representative; post workshop focus group

Patient representatives came to see health care professionals differently by making observations, for example about how GPs might be emotionally affected in their encounters with patients:

> "So if you're telling a story, it depends on how you tell it of course, but you can't help, if someone's been in pain for, you know, six months and they've tried everything and they're desperate, then you can't help but be moved by that, I don't think."
>
> Martin; Interview

Health care professionals were not always good at offering reassurance to their patients and their language was sometimes derogatory, referring to back pain sufferers as a "burden on society" (Pam; Interim review, Anon; Workshop Three, Anon; Master class), and likening them to items of mail when they were "lost in the system" (Pam; Interim review).

In their workshop feedback patient representatives reported concerns about understanding and being understood and this included problems arising from the use of medical jargon, especially at the beginning of the project. Expressing how they felt about this:

"[I felt] a bit inadequate really, because I didn't know what they were talking about, and then I was thinking, oh what was that acronym and by the time I'd decided that I knew what it was, or I didn't know what it was, I'd missed what was being said anyway. It makes you feel a bit inadequate, a bit left behind."

Christine; Interview

"[At first] I felt that I really didn't understand the language, they were talking about red flags and yellow flags and initially I was at sea."

Lynn; Interview

Concerns were addressed by the research team and the project participants agreed to not use medical terminology or health care jargon in the learning setting. Following this, patient representatives said they felt as if they were on equal terms and working towards the same goals as the practice teams.

Health care professionals, like most other professionals, have their own language for communicating about professional issues which may not always be understood by lay people. It is good practice for healthcare professionals to convey health care information using plain English so that it is understood by members of the public. In this study patient representatives reported the use of medical terminology and jargon by the health professionals as a barrier to their understanding and to their learning. Continuous discussions about how to address this and reminders to the health care professionals were aimed at trying to prevent the jargon acting as a closed barrier to patients' understanding.

The way in which the language of the project had to be negotiated after the start of the workshops illustrates a lack of preparation. The difficulties in understanding one another were addressed promptly and efficiently when this problem arose, as evidenced by patient representatives reporting that they felt more at ease after ground rules had been agreed. Patient representatives were given space and the opportunity to express how they felt about the quality of the dialogue and their feedback influenced a change. This helped patient representatives and health care

professionals to feel more at ease in the setting as the barrier of language was lifted.

6.1.2 The language of patients

Whilst the use of medical jargon acted as a barrier to communication in the initial stages of the project, the opposite was observed in relation to the voices of the patient representatives. In the workshops patients were hesitant to speak, but when they did and the practice teams responded, patient representatives found it reassuring to know that their comments had been relevant, helping the practices look at things differently:

> "You had all your post-its, you had your white boards, you had your brainstorming and it made you think about things. But, for me as a patient I thought about things and I thought 'I won't say that', and then you do say it, but it turned out to be relevant and the key thing there is don't be afraid to speak up. Just speak up and say it. It's amazing how people say, 'Oh, I hadn't thought of that.'"
>
> Pam; Interview

Most patient representatives said that they got on well together as a group and that they were given the opportunity to express their views. The project enabled the sharing of information that would not normally have occurred. Patient representatives described a positive learning experience in which they were given space to talk in the learning environment which was very supportive, as evidenced in the negotiation around the use of language. They felt they were part of the learning and they valued this:

> "As a whole thing, I think it was very, very professional. But it also had the informality that allowed people to express themselves and engage, and enjoy the event [the workshops] as a whole each time."
>
> Stuart; Interview

The listening activities worked both ways. The patient stories, read out by the patient representatives themselves in Workshop Three, were powerful in conveying the feeling of enduring back pain:

> "The feedback that we got from them [the practice teams] was that they found it quite powerful and inimitable to hear [our stories] and I don't imagine that it was news to them, but I think, in a way it kind of grounded them."

> Lynn; Interview

It was important to the patient representatives to be given the opportunity to tell their stories in order to share with the practice teams what it was like to have back pain and needing to seek help from primary care practitioners.

Being kept informed by the provision of up-to-date information, throughout the journey, was important to the patient representatives. It was relevant that many practices chose to review their patient information leaflets for their improvement projects. This illustrated the way in which patient involvement influenced the process and outcome of the project. Had the patients not been there to suggest an improvement project around updating patient information material, the practices could have developed projects using their own ideas, for example one practice initially aimed to improve access to diagnostic tests such as MRI and X-ray imaging. The influence of the patient representatives was recognised very soon after they were recruited to their practice improvement team:

> "At first the team was not committed to involving a patient, but after recruiting a patient representative realised that this added value to the team and helped with some ideas and contributions to the teams' small improvements."

> LIMBIC Practice Improvement Projects Report

> "In our particular LIMBIC project, this [patient involvement] has been invaluable and allowed us to make the changes we have made to our back pain service in the practice."

> Practice presentation; LIMBIC Celebratory event

The presence of patient representatives in the workshops was a constant reminder to the practice participants that their patients were there to be consulted for their views about their needs in the healthcare setting. It enabled a continuous open dialogue around healthcare provision, the introduction of change, and the effect of this on patients' lives. It reminded practice teams that patients were there to be helped and that listening to them was the most appropriate way to do this. There were several changes over the course of the workshops around the use of language. There was a shift in the language used to describe back pain. In the first workshop participants were asked to give four words they would use to describe back pain and this was repeated at the end of the final workshop. One patient representative described this exercise:

> "The words that came out at the first workshop that we had were, anger, frustration, agony, helplessness, hopelessness. At workshop number eight [the final workshop] the words were positive, self help."

<div align="right">Patient representative: service user film</div>

This altered language, which occurred across the whole group of project participants, suggests they were all shifting towards a new language and this reflected a shift towards new thinking. When the patient representatives requested that the health care professionals modify their language in order for them to be understood, this had an impact on their thinking as well as their use of language. They became more conscious of trying to be understood and checking with patients that they had been understood. The health professionals tried hard to communicate effectively in their co-learning relationship with patient representatives. At the same time, patient representatives made observations about health care professionals in relation to their approach to patients demonstrating their understanding of the sensitivities for health care professionals in delivering news that might not be welcome as illustrated earlier, "that's hard for a GP to say, isn't it?" (see introductory paragraphs Section 6).

The health care professionals were motivated by the openness of the patient representatives and were moved upon hearing the patient stories. By working

through initial difficulties and building on the positive aspects of the learning environment, the language barrier for patient representatives was removed and conversations flowed freely.

6.1.3 Communicating expectation

Patient representatives described how they felt negotiating their way through the healthcare system, trying to find out about what might happen to them. In this study the experience of joining the workshops late and not knowing what to expect was "like being the new boy in the middle of term" (Martin; Interview). Others described their engagement with health services as "going through the system" (Pam; Interview) and "being part of a process" (Stuart; Interview).

In this study the patient representatives learnt about the importance of doctors being open and honest with their patients when it came to talking the truth about back pain, they learnt that doctors did not have an answer to curing back pain and they needed to learn how to communicate this:

> "It may well be it's the person that gives the message. [name of a workshop speaker] gave it in a way that, well he made it seem like it was a light bulb going on, although with all, well I knew and I'm sure [names another patient representative] knew, well we all knew that, because we're long term back sufferers, that if a cure hadn't been found, you know, in the first year, then it was unlikely that it was going to be found. But we still probably didn't accept it, because…, well it was for me, it's the way you tell 'em."

> Martin; Interview

Some of the patient representatives had received different messages from health care professionals about how they should be managing their condition. Those patient representatives who had said they did not see the benefits of the project had embraced self-management behaviour for their condition and this could have contributed to why they saw little benefit of engaging in the project. Others said they had known but had not yet accepted that their condition was chronic and should be managed by them. It was their engagement with the project which helped them understand this.

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My reflection

I observed a group of patients who had already adapted their language when they first engaged with the project. They had begun to use medical terminology and acronyms, learnt through their repeated encounters with health care professionals. They used this language when speaking with health care professionals and they used it when speaking with each other. In the LIMBIC project, however, this was not enough. Many of them required translations of medical language into lay language. This occurred in the early part of the project and the structure and the processes were in place to enable the research team to address this. Soon after, if anyone failed to understand a term they were not intimidated to ask for an explanation and this created an openness which permeated the whole group and continued throughout the project. In the co-learning environment all the participants learnt from each other's experiences of communicating and learned better ways of making their communication more effective. This included listening.

Learning about the patient perspective

In trying to understand the experience of involvement from the patient perspective, the shift in the power dynamic between patients and health care professionals begins here. The use of jargon made patient representatives feel inadequate and there was a sense of hierarchy at the start, reflected in the lack of consideration for those who may not be fluent in the language of health care. As illustrated in the earlier theme 'feeling of togetherness,' this hierarchy was not evident later in the project. Respect was a key part of the relationship between participants and as the hierarchy diminished, language barriers disappeared and the comfort zone expanded. Patient representatives were open in their willingness to learn and in their expressions of frustration when confronted by barriers to their learning. Health care professionals were humbled by the approach of the patient representatives and the co-learners began to work together. Their respect for each other was a feature of the learning environment and the weight of the language barrier was removed. Anecdotes about "burdens" and '"red and yellow flags" were replaced by important narratives about the reality of living with pain. Change became a recurrent theme, and as this began to evolve, the participants were more prepared each time. Language was changed, the co-learning relationship strengthened, and a respectful approach showed participants at ease learning with each other.

Patient representatives learnt about the communication of feeling in the context of the healthcare consultation. In their usual encounters with healthcare professionals they were not used to experiencing much emotional connection, but in the discussions between health care professionals and patients in this learning environment, expression of emotion was part of the conversation and this was unique in their health setting.

6.2   Sharing memories and experiences

An important feature of 'it's the way you tell 'em,' was the way in which the patient representatives shared stories about their experiences of back pain which included their frustrations in accessing health services. The extent to which the recollections of their experiences dominated some of the group sessions was initially perceived as a distraction by some, but it is included because it was relevant.

In the context of the LIMBIC project, and reflecting upon the value of support groups, participants found that meeting with other patients who had the same condition led them to realise that their own experience was not unique and they thought about others whose back pain might be worse than their own:

> "It was for me, you know, listening to other peoples' experiences and realising that perhaps they hadn't, through their experience, hadn't had as good a treatment as myself, or as good an understanding as myself regarding back pain."

> Jane; Interview

Jane observed that through listening to others she had a better understanding and a more positive outlook about her condition. Another patient representative said:

> "One of the things that I really got out of the project I think was the opportunity to speak to others who were also back pain sufferers because you actually perhaps need to speak to others for the support..... I think if we can get out of this project the importance of information sharing and updating patients on what is available, I think that would be brilliant."

> Patient representative; Post workshop focus group

Another patient representative described the features of the LIMBIC project to a reader audience:

> "Good ideas could be shared with all practices, good communication with patients in the practice, and support where necessary."

<div align="right">Patient representative; article in BackCare Journal</div>

Patient representatives began to realise that the treatment available to people with back pain from National Health Service organisations differed depending upon the services available to, or commissioned by, their practice. Some patient representatives therefore felt fortunate compared to others because of the treatment they had been offered, and fortunate compared to practices who might not be engaged in the LIMBIC project:

> "I'm blooming lucky to live in an area that our practice is as it is, very fortunate, so I can't comment on the other practices, but I just understood that their constraints were a lot more than our practice."

<div align="right">Bob; Interview</div>

> "I think it's going to be a bit of a lottery for back patients as to which doctors are in the surgeries and those who have been on the [LIMBIC] project are going to get the best treatment is the way I look at it."

<div align="right">Christine; Interview</div>

> "The other thing that the project revealed to me was quite how patchy provision was in some areas."

<div align="right">Patient representative; post workshop focus group</div>

If some participants felt more fortunate, it should follow that some felt less fortunate, and one of them made this point. After describing the various approaches they had tried to help alleviate their pain they explained:

> "That's what it's [back pain] really meant for me, and in terms of
> primary care [pause] there hasn't been much of it."

<div align="center">Patient representative; Interview</div>

These observations link with the uncomfortable learning experience described in 'a feeling of togetherness.' The inequity in provision of health services reported by the patient representatives was difficult for them to understand and to accept. It was the trigger which prompted some of them to remain connected to the project well after the workshop phase and to get involved in dissemination and commissioning processes. Some were motivated to continue their involvement in the hope of influencing future service development processes, and this did occur, as shown in the example below:

> "I learnt lessons through my involvement with LIMBIC, and so,
> I believe, did the practices that took part. It is now time to pass
> on those lessons."

<div align="center">Patient representative; BackCare members Bulletin</div>

In the earlier 'feeling of togetherness' sub-theme, 'transition to a new role', showed how the patient representatives took a more controlling position in the project, such as when they took leading roles in the film. For many of them there was also a transition in their thinking about how to approach their condition; a transition to a self-help approach. This was an indication about what motivated the patient representatives to take part in the project. They felt that they were in a position of readiness to take control of their condition. This concept links also to a later theme of 'really wanting to make change.' Conversely, patient representatives who reported that they did not see the project as having achieved very much described how they had taken a self-management approach towards their condition for many years. They had probably expected to learn something new about how to manage back pain and when they did not, they were disappointed in their expectations for the project. They might have wanted to find out if there was something new to help them manage their condition.

Promoting self-management of back pain was an explicit aim of the LIMBIC project as it reflected the clinical guidelines available to GPs to support their decisions about managing back pain. So when self-management emerged as a key piece of learning for the practice teams, it was not unexpected. Most practitioners saw it as a reinforcement of their knowledge, but the fact that it was also a key piece of learning for many patient representatives had not been anticipated:

> "That was a big learning thing because it's something you're going to have to live with and manage yourself. That was something that I speak regularly myself about, that you're going to have to manage your own pain and there's nothing more people can do for you."

> Pam; Interview

When patient representatives first started to talk at length about their experiences of back pain it seemed to stray from the project aims; but it became necessary that the patient representatives knew about each other's perspective on back pain to allow them to develop in their thinking.

Discussions within the workshops provided the opportunity for practices to consider setting up self-help groups as part of their improvement work but this idea did not lead to any significant development and some patient representatives expressed disappointment about this:

> "I think that [support groups] would be a great idea and talking to a few of the doctors, none of them said they thought it was a bad idea but none of them seemed to be willing to do anything about it [laughs] if you know what I mean."

> Kevin; Interview

Sharing their experiences allowed patient representatives to benefit from discussing how they managed living with back pain, and whilst they sometimes showed differing opinions about what it was like to live with back pain, there was an empathy among the group which helped them move forward individually in coping with their condition, and as a group in supporting the aims of the research project.

Overall, the sharing of experiences which occurred at multiple levels was a key component of the learning initiative and emerged as a feature of the user involvement experience which enhanced the learning and contributed to the impact of the LIMBIC project:

> "I think these types of programmes involving people, patients basically, I think they're great, I think they should do more of them because I feel that it's something which the patient would become involved in and I can't see any negatives from it."

> Kevin; Interview

Kevin is clear in his comment about his positive experience of involvement. Sharing stories about experiences and memories allowed patient representatives to get to know one another. The sharing of personal stories had a cohesive effect within the group of patient representatives, leading to a better understanding of the health care professionals they engaged with as recipients of health care. The patient representatives shared their past experiences with each other and with the health care professionals at a professional level where they were equal as co-learners and this deepened their understanding of one another, described by one patient representative as "a most rewarding experience" (article in BackCare members bulletin, November 2009).

The patient stories were a milestone in the learning initiative and this sub-theme illustrates how listening as well as hearing was the way the narrative evolved. 'It's the way you tell 'em' applies to everyone's narrative.

My reflection
During the workshops when the patients met as a group and spoke with each other about their back pain, I thought about what influence, if any, this might have in relation to the project outcomes. Looking back, I can see that it was important for this to happen. The patient representatives were bringing their own individual experiences to support the principles of the research project, but, equally importantly, they shared similar experiences and they began to develop ways of using these disclosures to come together with shared goals. I realised it was

important to remember that the past is just as important as the present and the future in planning projects which involve patients, and to allow space for this to happen.

From the patient representatives' perspective, they did not see themselves as recipients of health care, but as people who wanted to collaborate with health care professionals to discuss goals for improvement for managing their condition. Patient representatives saw themselves as co-creators of their health management strategy, where the importance of dialogue and language were paramount.

Learning about the patient perspective
In trying to understand the experience of involvement from the patient perspective, the sharing of experiences occurred as a natural consequence of the LIMBIC project and the environment was conducive to this. The patient representatives were in a safe setting, due partly to the preparatory work that was undertaken by the research team, but also due to the receptive nature of their practice team co-learners who were learning to listen as the project evolved. Sharing stories led the patient representatives to learn about the inequity in the health system in terms of provision of services and quality of care. They accepted this even though they saw it as problematic. This reflected their eagerness to focus on the principles of the project which were about improvement. They hoped to change some of the inequities they had observed. The patient representatives were dignified in their acceptance of ambiguity in their learning experience and quickly depersonalised any conflicting priorities when the goals of the project were at risk. Project priorities superceded the unfairness they experienced and the goals of improvement remained constant. Practice teams also allowed the goals of the project to take priority over any personal or practice-based agendas. Describing the experience as rewarding indicated that patient representatives gained personally from their engagement in the project and wished to tell others about this, for example sharing their experiences by writing articles. This tells us their experience left them confident to convey the key messages about the LIMBIC project because they felt qualified to do so and able to utilise the right language. They knew how to 'tell em.'

6.3   No time to listen

Patient representatives described how doctors did not have enough time to listen to what patients wanted to say to them, in the clinical setting. In the LIMBIC workshops, patient representatives were given the opportunity to tell their stories and they described how being given time to do this was important to them:

> "And I think wanting to tell our story to the healthcare professionals was important for us because we could have that extra little bit of time and be listened to whereas I think, I know for myself and possibly speaking for other patient reps, when you go to the surgery and you sit in a waiting room, and there are twenty other people waiting to see the GP, and people going in and out, in and out, there is very much the feeling that I go in, I quickly say, 'this is what's happening', I get my prescription, and I go. But it was really quite nice to be able to say, 'well actually, this is how back pain affects my life'. And it isn't just about dealing with the pain, it's dealing with the implications of having chronic pain for living, the quality of life that one experiences and how it impacts on you."

> Lynn; Interview

In reflecting on her experience of telling her story, Lynn described what most patient representatives alluded to; a change from usual practice in her engagement with health care professionals. In the LIMBIC project they were afforded a luxury that did not usually occur in the GP consultation. They were given the time to speak openly about what it was like to live with back pain, which had not happened before:

> "And everyone seemed to listen to our stories very intently, everyone that was there. I'd forgotten about that workshop, that was a good workshop, because we'd all told our stories and people were so interested and very keen to listen."

> Christine; Interview

Doctors were portrayed as being too busy to listen. This was starkly reflected in the acting in the LIMBIC film where a patient, in role as a GP, interrupted the patient who was talking to her GP, avoiding eye contact and demonstrating little evidence of caring (Figure 24).

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In their group discussions, patient representatives discovered how different practices offered different sorts of services including the length of time they could spend in consultation with their GP:

> "Well, the different practices, this I felt came up in the workshops, the different practices, they act differently because of their time restraints they have per patient."

> Bob; Interview

Patients said at the outset of the LIMBIC project that they were there because they wanted to be listened to and, as part of the project, this did happen:

> "They began to listen to patients. They were listening to what we were saying."

> Christine; Interview

One patient representative described her surprise on realising that doctors might want to listen to her when she joined the LIMBIC project:

> "You've suffered all the time, and you've felt that nobody listens to you, then, all of a sudden, you're a patient rep, and you've got these doctors around, you are expecting them to listen to you."

> Andrea; Interview

Patient representatives described how their engagement with the LIMBIC project had helped GPs to understand the importance of spending more time with their patients:

> "But now I think they will listen and perhaps ask a few more questions to find out just how that patient is really feeling deep down."

> Christine; Interview

The patient representatives were clear that in the clinical setting doctors were very busy doing other things and that this impacted on the amount of time they were afforded by their doctor. They agreed that as a consequence they felt they were not

listened to. A presentation included a summary about how this changed over the course of the project:

> "I was listened to. What I said, I could see was being taken on board, and that for me was important. That was really important and that's when I think we said 'we just want to be listened to' and we were listened to."

> Patient representative; Master class presentation

However one patient representative did not feel that anything was gained from patients telling their stories:

> "You're just, you're telling the same story, it's like, it's like reading the same book. How many times do you have to tell a story to get it [treatment] right?"

> Patient representative; Interview

Themes about time and listening prevailed throughout the data from the LIMBIC project; evident in focus group discussions, in patient interviews, in patient correspondence and in group meetings. There was an acceptance that health professionals in primary care could not afford their patients the time to discuss their condition. Linked to this was the suggestion that primary care professionals did not listen to what their patients had to say.

The impression of GPs not listening to patients arose from exploring the patient representatives' experiences of engaging with health care professionals in a co-learning environment. They described how the importance of telling the story was the way in which it was told, 'it's the way you tell 'em' and went on to describe features of their relationship which could be improved upon. Language, sharing experiences, communication practices and giving people time to tell their story can all contribute to improved communication. In this study, the patient representatives reflected on their experiences of seeking healthcare and identified discrepancies in the healthcare system. This suggests the existence of an organisational culture which individuals working in the system are unable to see from within.

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The LIMBIC project evolved as an interprofessional learning experience. There was an environment which created time for listening and this was valued by patient representatives and practice teams. It is relevant that this sort of valued co-learning opportunity is explored in future similar learning situations in order that the important features can be identified and built upon.

My reflection

It was hard to listen to patients describing their experiences of frustration in accessing the health care system and not being listened to by those whose role it was to provide health care for them. Irony unfolds in that the approach to managing back pain is about listening to patients in order to negotiate treatment goals. It was not a surprise to me that patient representatives talked about their interactions with the health care system and the restrictions in the time they had to discuss their condition and their needs. It was, however, a surprise just how much they talked about this being a problem, and a problem for all of them. Some of the patient representatives accepted that doctors were busy doing other things and could not spend as much time with their patients as they would have liked. I had not expected that patient representatives would describe these experiences to the extent they did, in the context of a research project, and this made me realise how much of a core concern trying to be heard was for them.

In the LIMBIC project, due to patients being able to give their views on the projects being designed by practice teams, and due to practice teams being willing and able to listen to patients, it was possible to effect change and this led to an attitudinal change on the part of the health care professionals towards the value of involving patients - a major learning outcome.

Initially the 'feeling of togetherness' outlined how participants engaged in a co-learning environment in such a way that they felt 'togetherness.' An environment had been created which enabled learning together to become enjoyable and for changes to take place. In 'it's the way you tell 'em,' there was a shift in the way people communicated in the co-learning environment which allowed the majority of the participants to better understand one another. This, coupled with the learning

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environment and the improved language, created the setting which made it possible for changes to be implemented.

Learning about the patient perspective

In trying to understand the experience of involvement from the patient perspective, the setting of the LIMBIC workshops allowed for a different relationship to develop between patients and health care professionals. The usual dynamic of the relationship disappeared and patient representatives were given the time to be listened to. The setting of the conventional clinical consultation, like a stage, seems to create boundaries and limits to conversations and this setting is probably familiar to most people. If the setting for the clinical encounter were different, if it was to be created more like the setting in the LIMBIC project, where conversation flowed more freely, then an improved dialogue could occur. The setting was a break from the norm and it created an environment where open and honest dialogue occurred. It conflicted with the messages which were being delivered by patient representatives when they described the problem of not having enough time with their GP. Most of them seemed to accept this as inevitable. Whilst the health service has limited resources and cannot offer unlimited services to its users, the patient representatives appreciated the co-learning situation in which they had more time to talk to GPs and GPs had more time to listen to them. The patient representatives realised that they could influence changes in practice and this is what they went on to do.

6.4   Summary of Theme 2: It's the way you tell 'em

Figure 28 illustrates the subthemes contained within the theme of 'it's the way you tell 'em' and the principles which developed from them. When exploring complex systems and processes, communication frequently arises as an area for improvement. The patient representatives, by sharing their experiences in a co-learning environment, and seeing that they were listened to, saw that they were also influencing the patient experience for those patients in the future who would seek health care from their practice. They saw how their involvement in this study, which included dialogue with their health care professionals, could lead to a renewed

understanding for each other. Being able to engage in discussion helped them to communicate their passion for achieving change.
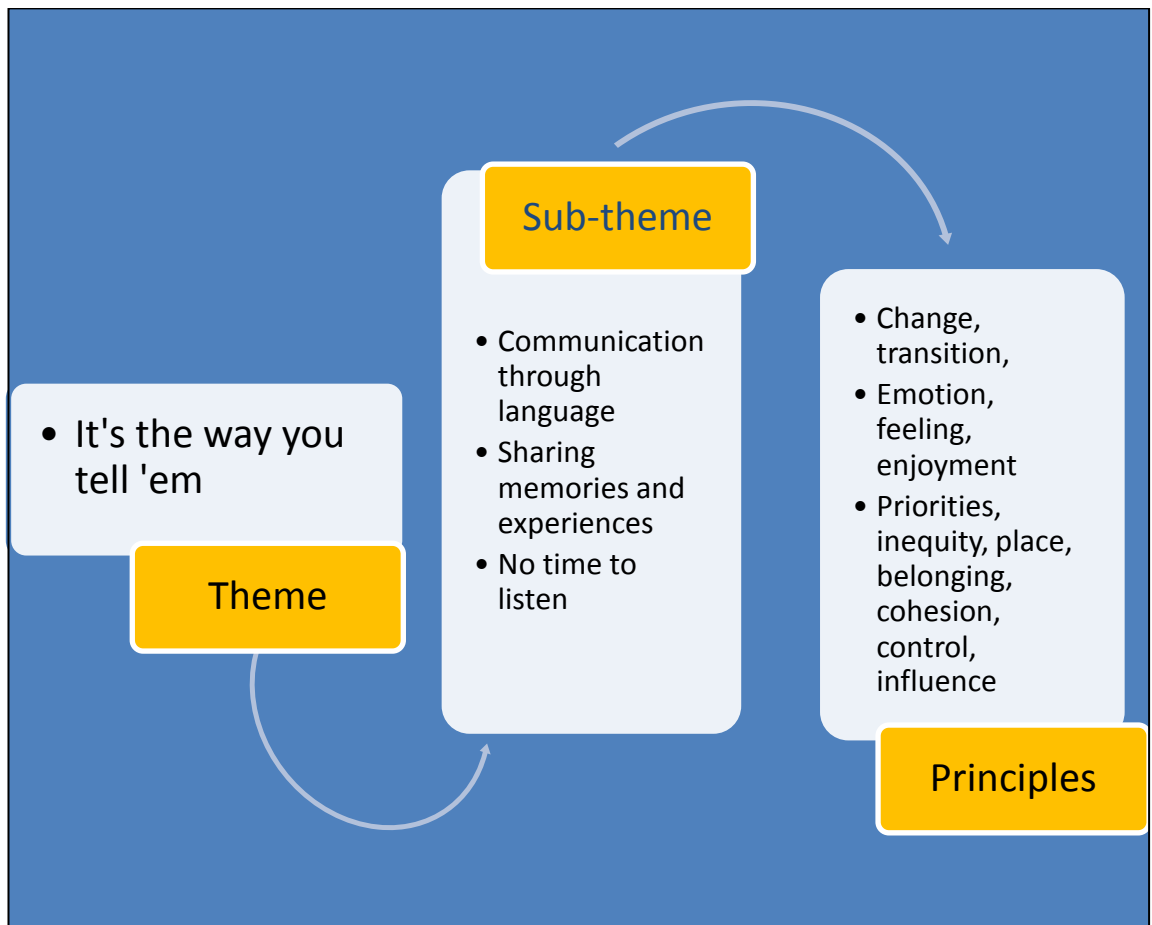
Figure 28. 'It's the way you tell 'em' - themes and principles

7. Findings, Theme 3: Really wanting to make change

The first two themes have highlighted the importance of communicative processes for patient representatives and the other study participants in their co-learning activity. Patient representatives referred to their motivations for participating in the LIMBIC project and this next theme illustrates their desire to effect change and the nature of some of the changes which occurred as a consequence of their engagement.

'Really wanting to make change,' showed the ways in which the project as a whole influenced change, and in particular the role of the patient representatives in these changes. Their experience created new ways of understanding ('a renewed understanding') which in turn provided a catalyst for attitudinal changes and the conquering of previously held beliefs ('a shift in attitudes, beliefs and perceptions'). This led to them changing their behaviour ('a shift in behaviour') and an ultimate shift in the overall balance of power ('the nature of the shift in the balance of power'). See Figure 29.
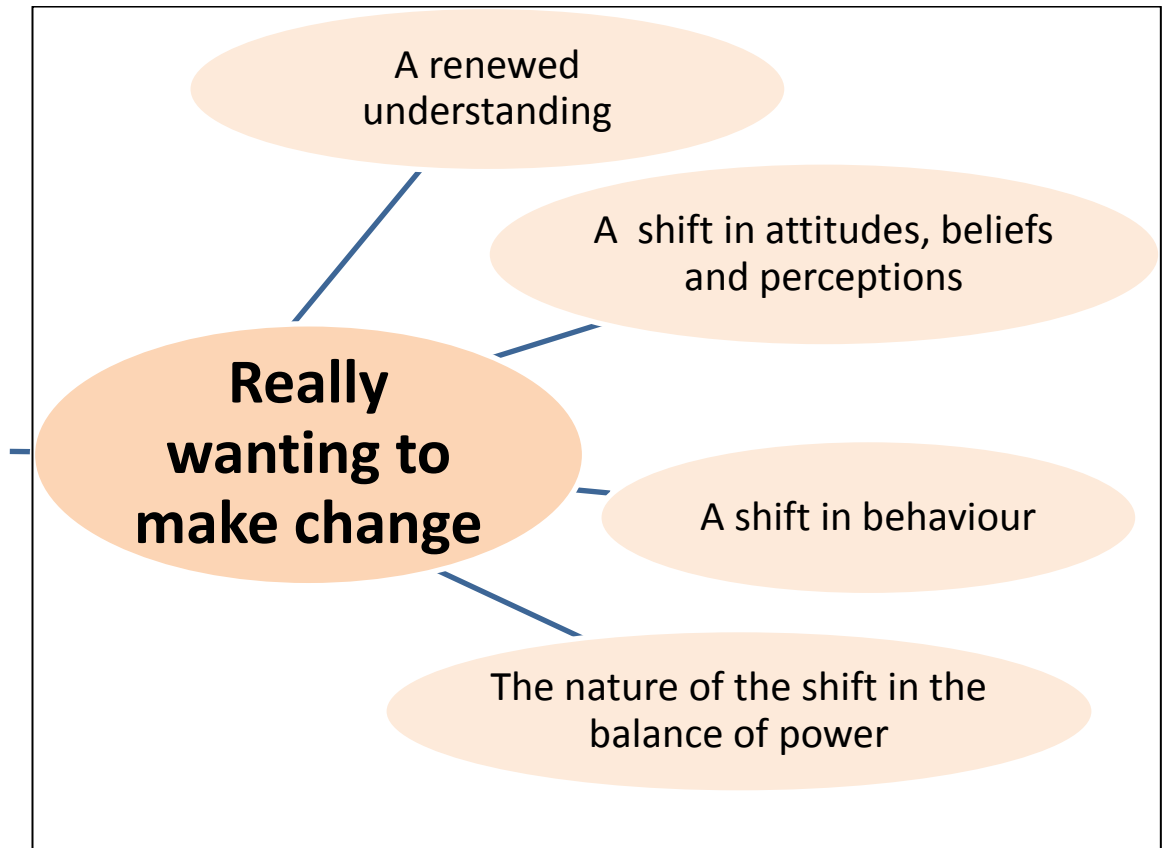
Figure 29. Sub themes for 'Really wanting to make change'

Changes occurred at several levels throughout the LIMBIC project and this theme highlights the various ways in which the patient representatives influenced change. Attitudinal and behavioural changes in the workplace featured and power sharing took effect.

7.1   A renewed understanding

There was no explicit process for identifying patient representatives' motivations for joining the LIMBIC project but many of them articulated their reasons. For many, it was their desire to help others seeking health advice for back pain. A genuine compassion for others and a desire to help others was a key motivating factor for patient representatives to join the project:

"If I could be of any use to anybody else I suppose to stop them having the hard time that I had when I first damaged my back, I don't want anyone to go through that because it really was a nightmare, but now I feel if I can help anyone else then I'm happy to do so."

Christine; Interview

Wishing to help others being the reason for patient representatives to get involved, was not a surprise expectation to the research team, but patient representatives could have had other reasons which they might not have articulated. Some did expect to learn about their condition and some had their own agenda as described by one patient representative:

"I suppose, in the back of my mind, that having contact with health professionals I might be able to pick their brains to find some kind of solution to my own health problem, and that turned out of course not to be the case. It wasn't set up to do that, but that was a kind of, if you like, it was a bit of an agenda, a hidden agenda on my part and I admit to that."

Lynn; Interview

Patient representatives realised through their involvement in the LIMBIC project that a self-management approach was the right approach for their long term condition. Some acknowledged they had expected this to be the case and the project reinforced it for them:

"One of the most exciting ones [guest presentations] for me, and I use the word not lightly, was the one establishing that back pain and the ownership from the profession, that there isn't a magical cure out there, that we don't know. We just don't know at this stage. To have that owned and then to also put the onus back on the patient to take responsibility for themselves, accept where they're at, don't allow that to limit yourself because I think that a lot of other patients had been doing that also, and to manage yourself and live your life to the fullest of your extent."

Stuart; Interview

Stuart uses the word 'exciting' to describe an event within the learning environment which was about patients' acceptance of their condition as long term and he acknowledges this as an unusual word to use. The event he refers to, which has

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been referred to several times throughout this thesis, was that of a guest lecture from an expert in pain management. The excitement he refers to is about the delivery of that particular message, the speaker's open and honest style, and the impact of the presentation on both patient representatives and practice teams. Having the facts laid before them, being open and honest about the prognosis and being able to talk about this between health care professionals and patient representatives changed the tone of the co-learning environment. Patient representatives and healthcare professionals became more at ease talking together about most issues and especially about the long term expectations for someone with chronic back pain. They began to develop a renewed understanding.

Patient representatives were helped in understanding their pain and they learnt to adopt strategies for managing pain:

> "I personally have benefited a great deal from the experience, taking full responsibility for my condition, accepting the limitations that are there."

Patient representative; conference presentation

They also understood the relevance of psycho-social aspects of pain and the appropriate management of pain when acute episodes occurred. Within the LIMBIC project, at first, the discussion sessions with patient representatives consisted of stories about frustration and the continuous search for a solution which they came to realise was not necessarily the right thing to be doing:

> "Further, as a whole experience, I learnt, I got a very important piece of learning out of it, and for me, that learning was, there is no easy answer."

Lynn; Interview

Not all patient representatives appeared to alter their understanding as a result of attending the workshops. One suggested that the presentations were beyond their level of comprehension:

"You know, what I heard from the people that were coming in and giving the talks and how we discussed things, I think was too much over my head."

<div align="right">Andrea; Interview</div>

Another patient representative expressed a view that the structure and content of the workshops influenced his poor understanding of the learning:

"Had there been more time for people to talk together then you bring out more views and discuss those views and maybe have a better understanding."

<div align="right">Bob; Interview</div>

"Well I found as a patient representative when you got to the afternoon parts and you had guest speakers I think they were more geared to educate the doctors and the practices rather than the patient representatives because I didn't understand it half the time."

<div align="right">Patient representative; Interview</div>

Some patient representatives said that what was being presented in the workshops did not enable them to learn a great deal:

"I didn't learn much. Unfortunately that's, from my point of view I didn't feel I learnt much."

<div align="right">Bob; Interview</div>

The setting which was created for co-learning did not work for some people. These people might have needed more time for their discussions. The approach to teaching and learning might not have suited everyone's preferred learning styles. Or expectations may have differed between individuals. Observations made by some patient representatives suggested that some were engaging in the project because they wanted to talk about their own experience:

"It was more about the peoples' personal experiences and their gripes and their pain than it was about the system."

<div align="right">Patient representative; Interview</div>

Other patient representatives were clearer about why they entered into the project:

> "I went into it open-minded, ready to learn and ready to say what was necessary."

> "I had no aspiration, expectation. I didn't know what it was going to be about and it was altogether a very, very pleasant experience. I enjoyed it."

Pam; Interview

Many of the patient representatives were better able to understand the difficulties and frustrations experienced by GPs and other health professionals and that doctors do not always have an answer for the medical conditions presented to them. Working with the practice teams helped patient representatives realise that a lot of hard work went on behind the scenes in the practices which they had not previously realised:

> "I was seeing things from a GP's point of view and a practice nurse point of view and a physio's point of view which I hadn't appreciated as a patient."

Martin; Interview

> "It's only through my involvement in the LIMBIC project that I realise quite how hard these people work and how hard it is for them to find even just the time to devote to the project. People are under a lot of pressure at work and I think that it does us good as patients sometimes, I think it helps us understand the system."

Patient representative; post workshop focus group

The co-learning experience of the LIMBIC project led to changes in perceptions for the patient representatives regarding the working of primary care practices. Patient representatives saw how the façade of "the receptionist's sliding glass door," concealed a culture of individuals working hard to provide care for their patients.

Patient representatives were not always understood by GPs. One patient expressed frustration saying that doctors needed to understand back pain better and that it was a deficiency in their knowledge base compared to other medical conditions:

> "Doctors need to understand chronic pain, chronic back pain. They understand everything else so why not chronic pain for backs?"

<p align="right">Andrea; Interview</p>

A couple of the patient representatives denied gaining an improved understanding but most of them gained new knowledge through their engagement with the project that led them to new understandings. They began to realise new concepts. Some expressed surprise when they realised they fitted into the medical model of a person with chronic back pain, one of them described her feelings as she listened to a presentation about the psychological impact of back pain:

> "But it was interesting to see how she [the presenter] broke it down, her diagrams, and her flow charts, she had a thing with a circle and you saw the circle with all the depression and anxiety and fear and this and this and this and you thought, 'oh, crikey, yes I've got it all'."

<p align="right">Pam; Interview</p>

Patient representatives used to think GPs could cure everything and described how their engagement with the project helped them realise that this was not the case:

> "It was an on-going condition that I would learn to manage, that there was no magic bullet, there was no cure. I think I thought it was very illuminating to see it from the GP's point of view and from the health care professionals."

<p align="right">Lynn; Interview</p>

Further methods through which patient representatives gained a renewed understanding included their experience of working on the improvement projects with the practice teams. They used the improvement tool called the Plan-Do-Study-Act (PDSA) cycle, described by one patient representative as "planting a seed" (Martin; Interview). Using this tool helped practice teams and their patient representatives to realise how the change cycle could be used to impact on practice routines:

> "I'd say that towards the end virtually everybody was on board, yes, they were looking at the wider picture and especially when we were looking at the later PDSA cycles, and engaging in individual GP groups with the projects to look

at certain aspects of primary care trusts and what was needed
to be implemented and how you would utilise a PDSA cycle to
review that, and then implement new actions."

<div align="right">Stuart; Interview</div>

Agreement about the learning which was achieved was not universal. One patient representative suggested that getting involved in helping a practice to change was not useful to him, "it's of no benefit to me, I'm a patient" (Bob; Interview).

Patient representatives recognised that they were part of a process that was about implementing improvements in the health care system, about trying to fix a system, and that the project was not there to allow them to address individual issues:

"We were a cog in a wheel, we weren't necessarily the entire
wheel."

<div align="right">Stuart; Interview</div>

Patient representatives described how, in their learning from the project, they came away with renewed understanding:

"So I came away perhaps with a real shift in understanding as
a result of the project."

<div align="right">Martin; Interview</div>

Although not all of the patient representatives exhibited a change in their understanding of back pain as a result of participating in the project, for those who did, their grasp of the project as a whole, including the teaching about back pain, impacted their ability to interpret their own pain. For the patient representatives who did not share the renewed understanding, they did not gain as deep an understanding of the purpose of the LIMBIC project. Given that a shift in understanding was shared by many of the participants, it was not a surprise to see this lead to shifts in other areas, namely attitudes, beliefs and perceptions, illustrated in the next sub theme.

My reflection

A renewed understanding occurred as a result of a learning initiative. This is not a surprise, but the different levels of renewed understanding were remarkable. The patient representatives, as well as the health care professionals, gained a better understanding of back pain and how to manage it which was an intention of the project but there was also renewed understanding about each other and about their roles. I was surprised to hear about the alternative experience of those who said they did not gain an improved understanding and therefore what appeared to be two opposing perspectives about the learning that was achieved by the individual participants. This could be explained by suggesting that patient representatives differed in their preferred learning styles which could have influenced their experience. Patient representatives who were further along their pain journey, having accepted it as a long term condition and had adopted a self-management approach were those who did not seem to gain a new understanding. This might have been because they did not need to.

As already mentioned, these patient representatives may have had different expectations from the project. Having accepted living with their long term condition for some time, they came into the LIMBIC project expecting to see changes in services for people with back pain. They did not understand that the project was just as much about teaching quality improvement to practice teams. This emphasises the importance of having a clear purpose involving service users so that they can develop realistic expectations.

For most of the patient representatives the renewed understanding sub theme explains the story of their moving in their acceptance and their understanding and learning to cope with back pain.

Learning about the patient perspective

This sub theme showed that many of the patient representatives were willing to learn and that they understood the principles of the project, just as much as many of the practice teams. They had the capacity to utilise what they learnt from the project to articulate the ways in which they had changed in their understandings. Their readiness to change showed their commitment to the project and the principles of the co-learning initiative. The acceptance of uncertainty about their condition

demonstrated their desire for information about their condition and their ability to see things from different perspectives. There was an overwhelming eagerness on the part of most of the patient representatives to understand their condition better, and to learn about it with practice teams by doing improvement work. Most of them yearned to influence future provision of services. Their desire to help others as a result of their engagement was a high priority. It was difficult for them to hear that a cure was not an option for their condition and they were dignified in embracing this and turned their experience into a form of learning, from which others could benefit.

7.2   A shift in attitudes, beliefs and perceptions

Throughout the project, people's perspectives about back pain differed widely. All the patient representatives came to the workshops with their existing beliefs about what worked for back pain and about how it might be treated. Whilst this represented a wide range of beliefs, as the workshops progressed, there was a shift towards a common understanding. Many participants changed their original beliefs about what worked for back pain and how to manage their condition. Patient representatives and health care professionals alike understood that they needed to "change the way we think about it" (Martin; Interview). GPs were reminded about how back pain influenced peoples' lives:

> "I think it was a helpful reminder to GPs that having back pain isn't just about coping with pain, it's actually coping with a different quality of life."

> Lynn; Interview

The patient representatives observed how GPs came to believe that the change that was required was not just about patients accepting their long term condition but that the doctors needed to change as well. The doctors needed to be open and honest and to support patients in accepting their condition, allowing patients to take control of their situation and move forward. This links with the inadequate communication processes which were described in 'it's the way you tell 'em.' Patient representatives changed the way they perceived the consultation should be undertaken, recognising the need for two-way communication:

"When I first went to my GP surgery, if he gave me a leaflet and said, 'Look this is what's happened to you, this is what we're going to try, this is what we're going to do, this is what you need to do, if you follow these guidelines you'll improve', I would have been so grateful, very grateful indeed. Patient leaflets, informing the patient as you go along, keep the patient informed, that's the message I would like to put across. You know we are big enough, we can take it. You know if it's going to take six weeks, tell us it's going to take six weeks."

Patient representative; Master class presentation

This patient representative was speaking to a group of primary care practitioners about the learning from the LIMBIC project and demonstrated how, as a patient, it was possible to accept the reality, and that being open and honest about what to expect was what patients wanted from their GP. The delivery of this message illustrated how important it was for patient representatives to share their learning from the project with others.

Engagement in the project also enabled patients to see things from the doctor's perspective and acknowledge how difficult it was for them to know how to help people with back pain. They could take a different view about how, for them, referral to the right consultant or for the appropriate treatment did not always occur:

Patient rep	"It's [in] a way [like] having all these people with a problem and different symptoms, different needs and different solutions, getting them all into a sieve, if you like, shaking the sieve and some fall through the smaller holes and some fall through the bigger holes, but they'll be separated into the pathways that will help them. Does that make sense?"
Both	[laughter]
Interviewer	"Yes, it does actually. Did it feel like that for you?"
Patient rep	"Yes because sometimes I went through the wrong hole."

Patient representative; Interview

The sieve analogy illustrates the experience of referral for inappropriate treatment and the unpredictability of the clinical care pathway for people with back pain.

As patient representatives began to see things differently, they observed how GPs also changed their attitudes as a result of their learning through the LIMBIC project:

> "The doctors seem to have benefited. They are much more aware. They ask lots of questions. It is not 'boring' to them. It is good that they are happy to involve patients in their work. It would be good if practices were more proactive in involving patients in the workings of the surgery."

> Patient representative; Reflections Workshop Eight

Patient representatives came to believe that involving patients in service planning and delivery, as in the LIMBIC project, was of benefit in many ways. Some of the patient representatives had experienced not being believed by their health care professionals and throughout the project they observed a change in the way doctors interacted with people with back pain, now clearly believing their patients and taking back pain more seriously. An attitudinal change was observed:

> "I was surprised to see that refreshing an attitude come out and to hear somebody say 'well perhaps within the profession we ought to be thinking about how we are going to get people to accept where they are at' which is very difficult, and that came from feedback from doctors within that group, and also manage their expectations of what they think we are going to achieve at primary care level."

> Stuart; Interview

At the beginning of the project, when practices were considering their improvement projects, some patient representatives expressed a belief that lack of appropriate funding was the main barrier to improvement of services for back pain. Participation in the workshops, for example using the Plan-Do-Study-Act (PDSA) cycle to effect change, helped patient representatives and practice teams see the wider picture and their beliefs about implementing change altered.

Most of the patient representatives said that they themselves had changed the way they viewed back pain and the way they managed their back pain. The changed perspectives were a reflection of the collaborative learning experience in which they had engaged and their shared goal, with practice teams, of wanting to improve the

experience for patients in future. Having developed new beliefs and changed attitudes, their continued learning led to a shift in behaviour, described in the next sub-theme.

My reflection

The shift in attitudes and beliefs was not so much a surprise as a welcome finding about the impact of the LIMBIC project. Measuring attitudinal beliefs or demonstrating attitudinal change is not easy, nor is it easy to attribute attitudinal change to an intervention. But the changes in beliefs and attitudes described by the patient representatives and exhibited by their changed approach to management of their condition reflected the impact of their co-learning experience with practice teams. For me this was an exciting outcome which I will explore further in my attempt to identify specific influences of patient representatives' co-learning experience. It showed me that creating a certain environment, with trust and respect as integral components of the working ethos, professionals and patient representatives can work together to create change and an enhanced patient experience.

Learning about the patient perspective

This theme exhibits a prevalence of changed beliefs, attitudes and perceptions. Participants repeatedly articulated their altered views. They shared their experiences with health professionals who also learnt to see things differently. They were engaged in a shared experience which included a shared learning. Patient representatives felt the impact of their involvement by observing these changes. Their positive approach in talking about the LIMBIC project illustrated their belief that they were part of something important to them which was also important to the practice teams. The importance of creating the right environment for co-learning that can lead to change is clear.

7.3 A shift in behaviour

The patient representatives experienced the impact of their involvement on the practice teams. They saw GPs change their views and the way they managed patients with back pain as a result of their change in attitude. They described how they observed a behaviour change:

> "I think a lot of doctors will have come away from that [learning experience] thinking differently about how they are going to interact with their patients which isn't a very easy thing to do. And that impacted on me quite dramatically to know that you can have a positive impact with a patient representative and can really enhance the process."

> Stuart; Interview

Patient representatives described how they were now listened to and that this was demonstrated by the changes that were put in place by the practice teams. For example, some practices introduced longer consultation times for patients with enduring back pain as one of their changes for their PDSA cycle. Giving more time for patient consultations allowed GPs to undertake a holistic approach with their patients giving them opportunities to talk about how their condition was affecting them and there would be more time for the GP to listen to them:

> "But because the doctor spent all that time and also found out about his [the patient's] home life and what he was doing at home and how he was, you know, his day to day activities, he managed to sort of get the guy sorted to an extent that the admissions to hospital weren't happening and it was an amazing story, and I thought, that is unbelievable, that's just great."

> Martin; Interview

Patient representatives described how they saw that doctors engaged in the LIMBIC project gained a clear understanding of what was important to patients and how to help them in managing their condition. They had come into the project wanting to make change happen, and they saw it happen. They heard GPs describe the

interventions they were now using to help them better understand and manage their patients with chronic back pain:

> "To hear somebody say, "well perhaps within the profession we ought to be thinking about how we are going to get people to accept where they are at" which is very difficult.
>
> Obviously practices are implementing some of the changes and for me it's going to be interesting to see what the outcomes are."
>
> Stuart; Interview

The patient representatives were empowered through their experience in the LIMBIC project. They were initially apprehensive but keen to engage. Once engaged, they became active participants who quickly grasped the concepts which underpinned the project and they began to take a proactive approach, making suggestions for change and taking the lead when given the opportunity. Towards the end of the project patient representatives were confident to lead parts of the initiative in delivering the key messages of the project to others. Delivering presentations at conferences and educational events, writing articles in lay publications, and taking lead roles in the film which told the LIMBIC story were all examples of the shift in the balance of power which occurred. This is explored further in the next sub-theme.

My reflection

It was not necessarily expected that within the nine month timeframe of the workshops that such a shift in GP behaviour would be observed. I expected that if this did occur that it would be more subtle. I had not expected it would be reported by patient representatives as part of the workshop learning. It was interesting to hear patient representatives talk about how observing this change had impacted on them dramatically. I am building a picture of what I set out to explore. There has been a lot of description of the co-learning experience and I am gaining an insight into this aspect of the educational initiative but I am also getting a sense of the emotional impact for the patient representatives and a sense that they are beginning to feel that they have influenced change through their efforts. Their story is real.

Learning about the patient perspective

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Patient representatives described how they were rewarded by seeing GPs change in their approach to patients with back pain. They too changed their behaviour from being passive in offering opinions, to taking a lead in telling the story. Patient representatives became assertive as they realised that the impact of a shared endeavour was going to be more fruitful than one which was led by health professionals alone.

7.4   The nature of the shift in the balance of power

The renewed understanding followed by the shifts in attitudes, beliefs and then behaviour occurred as the LIMBIC project progressed. Effort had been put in to the creation of an appropriate learning environment and this was recognised and welcomed by the patient representatives who said they felt equal "everybody was equal in it all" (Pam; Interview).

After an apprehensive start, as the project progressed, patient representatives began to enjoy their participation in the workshops. Towards the end of the project there were situations where, rather than playing out participatory roles, they were in control. In the making of the LIMBIC film patient representatives took on lead roles. Their confidence increased as the project progressed and when they observed discrepancies or felt they had a better idea, they "were able to say, 'hang on a minute' " (Stuart; Interview).

Patient representatives made presentations at the master class and at a number of conferences after the series of workshops were completed. They led seminars and workshops and were sought by other organisations for their expertise. Their role has extended to influencing health care commissioning, the impact of which might take some time to be observed:

> "Changing the way services are commissioned was never going to happen overnight. What LIMBIC has achieved is a significant change in the clinical management of back pain and commissioning approach of the PCT."

GP Commissioning lead; LIMBIC Project Report

The LIMBIC improvisation film showed the way in which GPs approach their patients in the consultation both before and after their exposure to the learning from the workshops. The aim of the story told through the film was to demonstrate the changes they made in practice as a result of their learning. Patient representatives portrayed a deep understanding of the role of the GP in the back pain consultation and their sensitivity towards their patients' needs, demonstrating a shift in GPs' attitudes towards patients with back pain and a better understanding about how to engage with them in the context of the clinical consultation (Figure 24).

A member of the research team observed:

> "The main message is that we probably should be spending a bit more time in convincing people that desperately looking for a diagnosis may not be the best thing to do. It may be much better to put all your efforts into finding something that makes it easier to cope with back pain or to cure the back pain or whatever you do with the back pain, the stories are about frustration, are about sometimes desperation, but the underlying theme is they had the wrong information, they were not given the right information at the right time that made them see that this desperate search for a diagnosis may not have been the right thing for them."

Research team member; source not disclosed

Engaging patient representatives in the LIMBIC workshops was meant to assist practice teams make improvements which reflected what was important to patients, by involving patients in the improvement process. Because the patient representatives wanted to make things better for patients in the future, they were committed to making a difference and their presence and their enthusiasm for change made a difference to GP behaviour. The patient representatives reported that they too had changed the way they viewed their back pain and within the context of the LIMBIC project their increased confidence and assertiveness, backed up by their changed understanding of back pain was typified in their role play in the LIMBIC film and in their language. Some of them continued to engage in the dissemination activity associated with the LIMBIC project.

My reflection

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The research team and the practice teams were all surprised by the way in which the patients involved in the LIMBIC project evolved in their role. Many probably thought that they would seek opinions from patient representatives and take these opinions into account when they decided upon their activities for improvement. To see the patient representatives take a lead role in many of the activities that occurred, especially towards the end of the project was certainly a surprise. The creation of the environment of trust and openness were key features which influenced this and giving space for patient representatives to share their experiences and to get to know their co-learning colleagues were contributory factors. But seeing them lead the way in sharing the story about learning in a way that allowed others to learn was an unanticipated outcome of the project. In some ways it changed the focus. The key messages from the LIMBIC project were about using improvement methods to change practice and making improvements in the management of patients with back pain. But another key message was about the importance of setting the scene so that the experience and expectations of the service users (patient representatives) were optimised for interprofessional learning, or co-learning, and to facilitate change.

Learning about the patient perspective

The theme of change is prominent in this study. Moving from a readiness to change at the start, and then observing change was found to be rewarding for the patient representatives. Progression towards leading the change, and then sharing the change, demonstrates the importance to them of their commitment to the project and to others who may seek health care advice for back pain. Receiving clear and accurate information at the start of the project was very important to the patient representatives, and they valued this. It was also important to them to get the environment right for learning. The geographical location, being out of the practice, and the feeling of being equal were important contributory factors to the co-learning experience. Learning together included learning about each other, that is, learning about other patient representatives and learning about members of the practice teams. Learning about how practice teams worked led patient representatives to change how they viewed GPs and the way they worked. Along with their willingness to learn, most of the patient representatives and practice teams brought with them a willingness to change and this, combined with the environment which was

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conducive to learning, led to most of them becoming part of the change. The shifts that were observed were experienced together by most of the participants of the co-learning initiative and show how patient representatives got what they wanted; they saw change happen.

7.5   Summary of Theme 3: Really wanting to make change

Figure 30 illustrates the sub-themes and principles of the 'really wanting to make change' theme. The principles of this theme came from the heart-felt desire of the patient representatives who were placed in an environment of trust and brought with them a readiness to change and a willingness to learn which was then ignited by the catalyst of energy from the group of enthusiastic change-makers, the research team. The passion for a changed patient experience was already present, and this enthusiasm permeated the participants of the project creating a shared experience with a shared goal. Patient representatives were observing change; they became part of the change and then began to lead the change. They then went on to share the change with others as they led the way in sharing their story. The patient representatives, in this context, became part of the infrastructure which supports the delivery of health services.
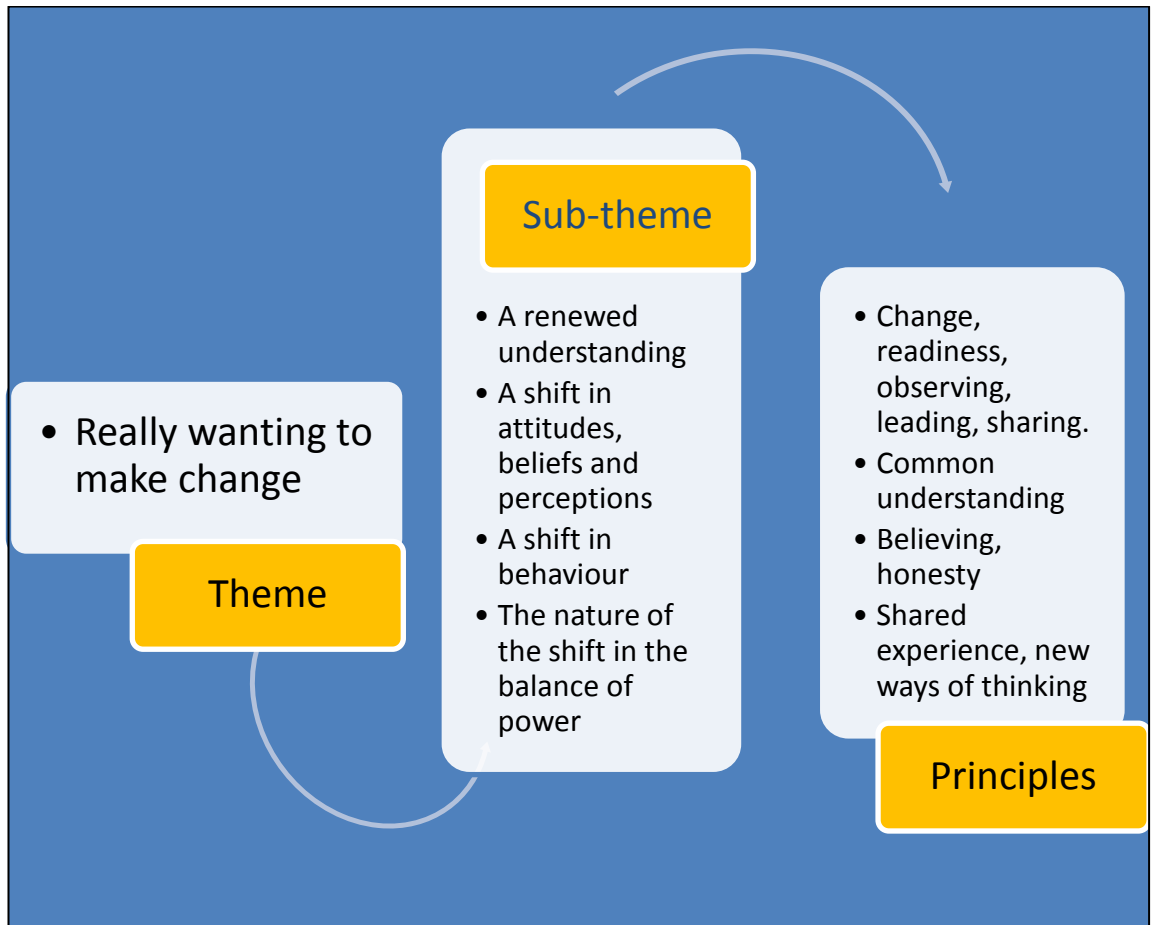
Figure 30. 'Really wanting to make change' - themes and principles

This theme illustrates the way in which a renewed understanding was gained from the learning process and this led to changes taking place. The involvement of patient representatives throughout the research journey of the LIMBIC project led them to take the lead in sharing the ways in which the learning from the project was shared with the wider community. The passion for change which patient representatives brought to the project, often based upon past experiences of unsuccessful encounters with health services, dominated the project outcome in a way that was sometimes quite subtle but which gained momentum as the project progressed. The carefully orchestrated learning initiative encouraged all the players to engage together in order to optimise the strengths of each of them. Health care professionals brought their knowledge, skills and experiences in a professional capacity and patient representatives grounded them in bringing their own true life

experiences which moulded the shape of their thinking about how they could improve the experience for their patients in the future. Patient representatives described their co-learning experience which was built upon a sometimes hidden past of anger, frustration and regret. Patient representatives were open about what they felt about their health experiences and their health service. In doing this, they could not be ignored. As they re-lived their healthcare experience through their experience of being involved in this project, this time they were listened to, and this time they were heard.

7.6   Developing this storyline

The first of the three key themes to arise from this research was about the creation of an environment for learning which was specific to this project and which patient representatives described in comfort terms as a 'feeling of togetherness.' It allowed the research participants to understand one another and offered them the opportunity of seeing things differently. According to the patient representatives, the setting facilitated an atmosphere for learning and sharing and revealed some features about communication between health professionals and patients, described in the theme 'it's the way you tell 'em' which explored the benefits of trying to use language which can be understood so that patients and health professionals can work together to achieve common goals. 'Really wanting to make change' showed how a renewed understanding was gained from the learning process which led to patient representatives taking the lead, being given permission to do so and co-producing changes to healthcare systems which would clearly benefit patients in the future.

Involving patient representatives in the co-learning opportunity with practice teams and exploring their experiences through a further research initiative highlighted some of the important issues specific to facilitating engagement such as managing expectation, creating the environment for learning and working in partnership.

Most strikingly of all, by gaining insight into the patient experience of involvement, these findings question why health professionals seek to involve patients in their

work, whether they have a clear aim for doing so, and whether they intend to listen and act upon patients representatives' comments and opinions.

8.   Discussion: a new model for co-learning

For the service users in this study, learning with, from and about their practice team co-learners impacted upon their experience leading to them feeling empowered and rewarded. For some there were unmet expectations and feelings of regret, reflecting a weakness in the preparation for their role. A co-learning partnership was formed as a result of managed expectations and creating a learning environment. From this study, a model for co-learning is proposed and the following discussion is structured to reflect the concepts which make up the model which will then be brought together with current evidence to support the case for the proposed co-learning model.

Co-learning between the patient representatives and practice teams in this study mirrored that described by Rutherford (2011). In the evaluation study (LIMBIC) they learned from each other, about each other and they learned together. At different times throughout the project they held different roles in relation to whether they were expert or novice, teacher or learner (Benner 2004). Their new knowledge about quality improvement, about the management of back pain and about primary care was applied to their improvement projects which in turn led to new ways of working for the practice teams. The patient representatives also moved to new ways of thinking about how back pain should be managed as they embraced the role of self-management. They learned about their clinical condition and about the ways in which the practice teams worked, which gave them a better understanding of primary care. All participants were involved in deciding the content of the workshops as they identified their learning needs and they participated in knowledge exchange through teaching others and learning from others.

Before their engagement in this study, patient representatives viewed health care professionals in primary care as if they were actors on a stage. They viewed the workings of the primary care system but they did not engage. Their role was passive. Service user involvement through the LIMBIC study permitted insight into the working lives of the actors and they engaged in dialogue together. They realised they could share goals and they applied this new learning to create changes in the clinical setting.

8.1 Development of the co-learning model and its components

Analysis of the data from this study led to the development of a model for optimising co-learning between service users and health professionals. This model for co-learning evolved during the data analysis process of this study and describes the creating of the ideal conditions for influencing change as a consequence of co-learning. Sources of data for the model had been provided by the service user participants of the study and therefore represent aspects which they consider are importance to them. The concept of co-learning in this context is about service users and health professionals learning together to influence change. The following account describes for each of the items from the model, their origin and their association with the evidence from the literature.

The proposed model comprises of four components which operate together at the same time and are interlinked with each other. These are; Preparation and Support for Co-learning, Environment and Values for Co-learning, a Rich Contribution for Service User Engagement in Co-learning and which lead to the development of a Shared Learning Expereince resulting then in the Co-learning Partnership. Each of the four components contains several sub-elements – see Figure 31 - the model for co-learning. Working together these components and sub-elements create the conditions for a shared learning experience which becomes a co-learning partnership.

Table 10 on page 205 summarises the data souces and supporting evidence from the literature.

Hypothesis: There is a relationship between the preparation and facilitation of the participants and the environment that enables the shared learning experiences and the development of a co-learning partnership.
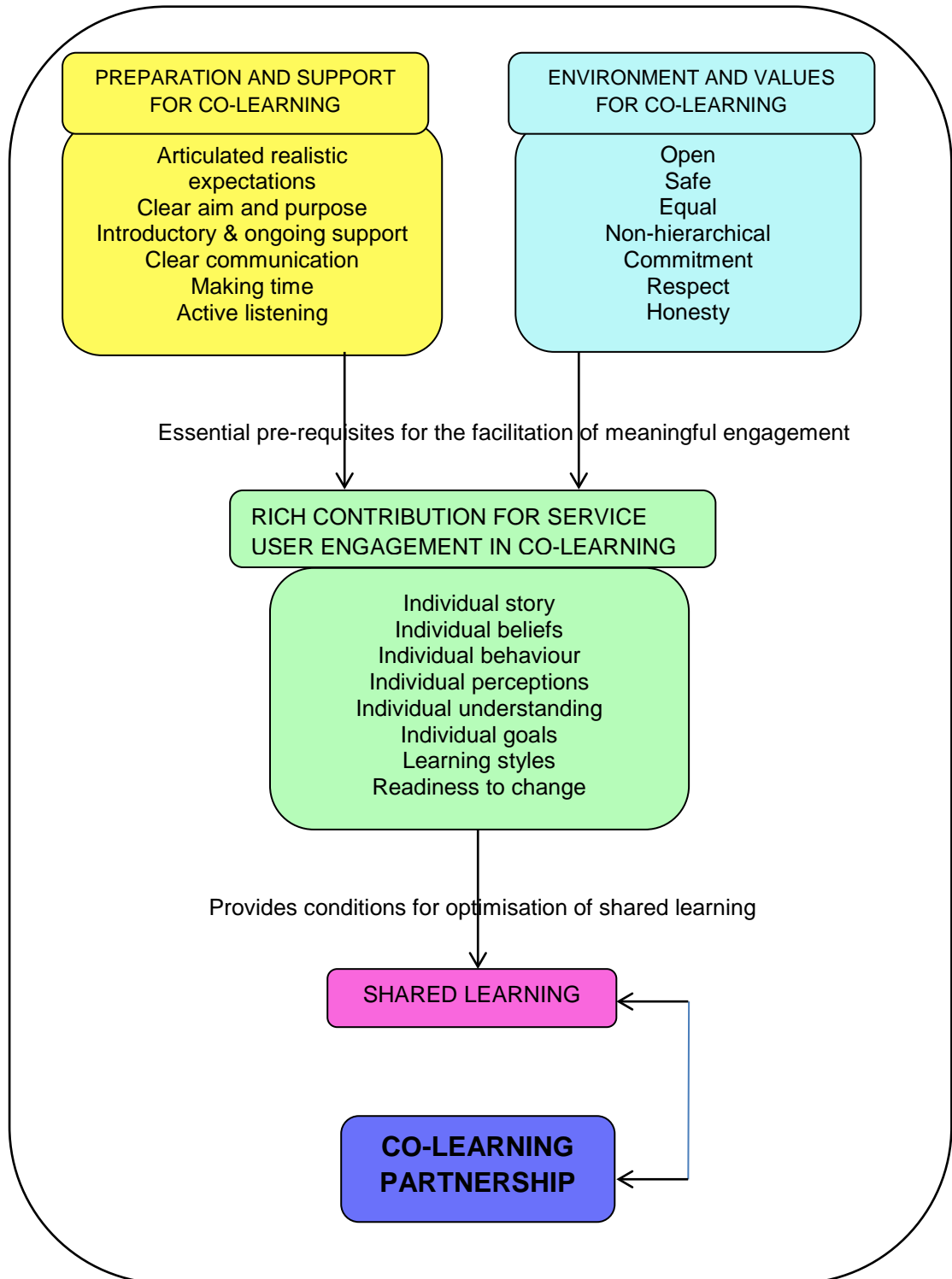
Figure 31. Outline model for co-learning to influence change

Component 1: Preparation and support for co-learning

All the elements of this component were derived from a range of data sources. There were six sub-elements.

i.   Articulated realistic expectations

        The majority of participants in the study described either a lack of expectation or a need for realistic expectations. Evidence for this came from one of the patient representative's reflections at the end of the series of workshops where the importance of good information at the start was said to be important (Section 5.1 Page 125 end of middle paragraph). Another patient representative expected to see other back pain sufferers benefit from his engagement in the project and felt this did not occur representing an unrealistic expectation as this was not intended to occur over the timeframe of the workshops (Section 5.2 page 135, Bob; Interview). Other evidence came mainly from patient interviews.

ii.   Clear aim and purpose

        Linked closely with the above sub-element the need for a clear aim and purpose for being involved in research was shown to be important to service users. A participant described how their involvement in the LIMBIC project had helped them understand primary care (Section 7.1 Page 177, Patient representative; post workshop focus group). Another was able to give an in-depth account of their understanding of the aims of the project and the quality improvement tools that were used (Section 7.1 Page 178, Stuart; Interview).

iii.   Introductory and on-going support

        This sub-element links closely with the above two elements. Participants in the study had been provided with introductory information and were supported throughout through a variety of mechanisms. Evidence to support this aspect of their experience is seen in the researcher notes from the pre-workshop meetings where it was observed that these sessions had helped the patient representatives gain a better understanding (Section 5.1 Page 125, Researchers review of pre-workshop meeting notes June 2011) and

patient representatives themselves reported the importance to them of sharing information (Section 6.2 page 160, Patient representative; post workshop focus group).

iv. Clear communication

The importance of clear communication was shown to be a central component of the experience of service user involvement and to be very important to the service users. The participant interviews provided the main source of data for this, for example there was criticism of the use of acronyms and medical terminology (Section 6.1.1 page 154 Christine; Interview, Lynn; Interview). Participants recognised the importance of clear communication in the clinical encounter (Section 6.1.3 page 158, Martin; Interview).

v. Making time

Making time was considered a valuable aspect of the educational initiative as a whole as was welcomed by the patient representatives. Where the expressions of regret were made this usually where time had been compromised, for example when the research team started the workshops before all the practices had recruited a patient representative, leading to them feeling regret at not being there at the start (Section 5.1 Page 126, Patient representative interview). Another patient representative expressed regret when they were unable to make time to attend the workshops themselves (Patient representative; post workshop focus group Section 5.1 Page 127).

vi. Active listening

Linked closely with the clear communication sub-element, active listening was described by the participants as an important contribution to their overall experience of service user involvement and was articulated in much of the interview data, for example when participants acknowledged that their viewpoints had been valued (Section 5.2, page 134, Lynn; post workshop focus group). Patient representatives described how when health professionals heard their (patient representatives) stories, it "grounded them" illustrating their active listening approach to working with the patient

representatives (Section 6.1.2 page 155, Lynne; Interview and Section 6.3 page 166, Christine; Interview). They welcomed the practice teams listening to them through the workshops (Section 6.3 page 168, Patient representative, Masterclass presentation).

The significance of this component lies in its relationship to the current knowledge about the experience of service user involvement such as that described by Armstrong et al. 2013; Barber et al. 2011b; Greenhalgh et al. 2011; Williamson et al. 2010; Lowes et al. 2010; Stewart 2008; Research Councils UK 2010b; Kreis et al. 2012; Martin 2012. Smith et al. 2008; Morrow et al 2012; Staley 2012; McKeown et al 2012; Mosconi et al. 2012; Oliver et al. 2001; Minogue et al. 2005; Frosch et al. 2012; Godfrey 2004; Cotterell et al. 2008; Staley et al. 2012; Ong and Hooper 2003 and Abma 2005.

The impact of these data builds on the current assumptions which show the importance of support, clarity of purpose and communication, as well as making time and active listening, are all important contributors to a respectful service user experience. Therefore the data in this study builds on current knowledge by adding to the evidence for focussing attention on the service user to enhance their experience of involvement.

Component 2: Environment and values for co-learning

The main issues identified in this component describe the conditions of the setting in which co-learning might take place and the values brought to the setting by the participants. The elements of this component were derived from data emerging from a range of data sources and especially the participant interviews. There were seven sub-elements.

i.   Open

Participants described the openness of the learning environment as having an informality that allowed them to express themselves (Section 6.1.2 page 155, Stuart; Interview and Section 7.2 page 182, Patent representative; Masterclass presentation).

ii. Safe

Participants expressed how they found the setting to be safe, for example, in terms of them not feeling inadequate about what they had to say (Section 6.1.2 page 155, Pam; Interview).

iii. Equal

Participants described their position in relation to the other learners as being equal partners (Section 5.2 page 133, Pam; Interview). The feeling of being equal was expressed by one patient representative in the feeling of togetherness theme when he metaphorically described his participation in the workshops as becoming part of behind the scenes, as opposed to being the recipient of healthcare in the context of the doctor's waiting room (Section 5.1 page 123, Martin; Interview).

iv. Non-hierarchical

Practices described how the patient involvement in their project was invaluable and helped them facilitate change (Section 6.2.1 page 156, Practice presentation, LIMBIC celebratory event). Patient representatives described how the practices and patients all shared good ideas (Section 6.2 page 161, patient representative; article in BackCare Journal).

v. Commitment

Practice teams demonstrated a real commitment to the goals of the project, towards improving the patient experience for people with back pain and patient representatives observed and commented upon this commitment (Section 5.3 page 138, Lynn; post workshop focus group). Some practices changed in their commitment to involving service users by taking it more seriously once they realised the value of service user input (Section 6.2.1 page 156, LIMBIC practice Improvements Project Report).

vi. Respect

Participants commented that everyone was respected and their contributions were appreciated (Section 5.2 page 133, Christine; Interview).

vii.   Honesty

Patient representatives appreciated the honesty of the clinicians in recognising the prognosis for people with back pain and the limitations for 'finding a cure' (Section 6.1.3 page 158, Martin; Interview and Section 6.2 page 163, Pam; Interview and Section 7.2 page 182, Patent representative; Masterclass presentation).

The significance of these findings is that they further the current knowledge base around the important features of the learning environment and associated values co-learning such as that reported by Katz et al. 2012; Caldon et al. 2012; Oliver et al. 2008; Morrow et al. 2012; Barber et al. 2011b; Esson et al. 2009; Andersson et al. 2008; Minogue et al. 2005; Wlater et al. 2003; Boote et al. 2002; Rhodes et al. 2002; Spencer et al. 2011; Aveling et al. 2012; Bassett et al. 2006; Morgan et al 2004 and Staley et al. 2012.

The impact of these findings is that the evidence base is supported further in relation to the aspects of the learning environment that can be influenced by both the research team and the service users in a co-learning capacity.

Component 3: Rich contribution for service user engagement

The elements of this component were derived from a range of data sources from the LIMBIC project as well as primary data from this study. There were eight sub-elements.

i.   Individual story

Patient representatives commented that hearing about other patients' experiences helped them put their own story into perspective (Section 5.3 page 138, Practice story board, celebratory event and Section 6.2 page 160, Jane; Interview).

ii.   Individual beliefs

Each of the participants held their own beliefs about how back pain should be managed and this was acknowledged to be a catalyst for sharing ideas (Section 5.2 page 132, Kevin; Interview).

iii.   Individual behaviour

Participants describe how they entered the project in an open-minded way, ready to learn and to give their input as necessary (Section 7.1 page 177, Pam; Interview).

iv.   Individual perceptions

Patient representatives had different perceptions about their experience of being involved in the workshops, one describing their position as that of an outsider (Section 5.1 page 127 Post workshop focus group).

v.   Individual understanding

This element reflects the different understanding held by the participants about what they learned from the workshops, one of them reflecting that they found the process map difficult and did not understand learning about the practices' processes (Section 5.1, page 128, Bob; Interview).

vi.   Individual goals

Goals differed between the participants, one claiming to expect some learning about pain management which was part of the learning but not the main focus (Section 5.1, page 128, Andrea; Interview).

vii.   Individual learning styles

This element reflects the different learning styles of the participants with regard to the workshops, one of them reflecting that the pace had been difficult to keep up with (Section 5.1, page 128, Andrea; Interview). Preferences for different formats for teaching and learning were also expressed (Section 5.1 page 130, Kevin; Post workshop focus group).

viii.   Readiness to change

Participants illustrated their readiness to change in several ways, one of these being seen in their altered use of language when they chose different words to describe what back pain meant to them at the end of the workshops compared to the start of the workshops (Section 6.2.1 page 157, Patient representative; Service user film). It was also acknowledged that practice teams seemed more willing to spend more time listening to patients as a result of their learning through the workshops (Section 6.3 page 167, Christine; Interview). Patient representatives also acknowledge their desire to change as a result of their engagement in the workshops, for example acknowledging their need to take responsibility for their condition (Section 7.1 page 175, patient representative; conference presentation).

Each of these elements describes what each individual brought to the learning environment and each one might have brought something slightly different. Throughout the learning experience, the individuality of these sub-elements came to be shared amongst participants so that some changes took place with respect to participants' beliefs, attitudes and behaviours. Through their learning they changed from their starting point in the project and through this they began to influence changes.

The findings from the Rich Contribution for Sevice User Engagement component of the co-learning model which describe how the individual participants' contributions relate to the learning experience as a whole build on the earlier research by Aranda and Street 2000; Blickem and Priyadharshini 2007; Barber et al. 2011a; Pandya 2010; Beresford 2007; Dewar 2005; Lindenmeyer et al. 2005; Tritter and McCullum 2006; Meyer et al. 2003; Maslin-Prothero 2003 and Oliver et al. 2001.

The significance of bringing together these individual characteristics in the wider model emphasises the uniqueness of this research in elaborating how each individual participants is recognised for what they bring to the research and how they can collectively use their characteristics, skills and experiences to create a unique co-learning experience to influence change.

Component 4: Shared learning experience

When these components are present and are combined the opportunity for a shared learning experience is created, illustrated in a comment from one of the practice teams at the LIMBIC celebratory event, describing how patients representatives had "benefitted enormously" from their learning experience (Presentation from a LIMBIC practice at the celebratory event, Section 5.1 page 124). Other patient representatives in their interviews observed the practice teams learning from each other describing this as a success of the project (Lynne; Interview Section 5.1 page 124; Stuart; Interview Section 5.1 page 124). Another patient representative described how the practice story boards had shown evidence of learning (Section 5.1 page 129, Martin; Interview). The individual aspects from the Rich Contribution component of the model became shared aspects, for example shared goals (Section 5.2 page 133 Christine; Interview), working together like colleagues (Section 5.2 page 136, Stuart; interview) all contributing to a shared learning experience (Section 5.2 page 134 Stuart; Interview). Patient representatives described how they had learnt from one another through their engagement in the project and they intended to share this learning with others in the future (Section 6.2 page 162, Patient representative, BackCare members bulletin).

These findings which form the shared learning experience build upon research by Fischer and Ereaut 2012; Greenhalgh et al. 2012; Armstrong et al. 2013 and Minogue et al. 2005. The co-learning partnership that is formed as a result builds on research undertaken by Caldon et al. 2010 and Armstrong et al 2013.

The presence of the elements of each component of the model which lead to the shared learning experience which becomes a co-learning partnership. The model support the hypothesis that there is a relationship between the preparation and facilitation of the participants and the environment that enables the shared learning experiences and the development of a co-learning partnership.

The importance of the co-learning model is that it is rooted in the data from this study, it has built upon current knowledge in the area of service user involvement and it draws upon literature from education and pedagogy to create a new model for a co-learning partnership between service users and healthcare professionals.

Component of the model	Sources of data	Key aspect of contribution to new knowledge
Preparation and Support for Co-learning	Workshop reflections Interviews Post workshop focus group Pre-workshop meeting notes Researcher pre-workshop meeting notes Masterclass presentation	Clarification of existing knowledge about important of training of service users, preparation for the role, support from researchers and peer support. Sheds new light on the negative aspects of the service user experience where failure to prepare with other co-learners and commencing their engagement late has an impact on their initial service user involvement experience.
Environment and values for Co-learning	Interviews Celebratory event. Article in BackCare Journal Post workshop focus group. LIMBIC practice improvement projects report Meeting notes	Clarifies existing assumptions about the importance of the preparation of the setting, context and mechanisms for service user involvement. Brings new knowledge about the importance of the personal values of the individual co-learners and the prior agreements about openness and honesty.
Rich contribution for Service User engagement in Co-learning	Celebratory event Interviews Post workshop focus group Patient representative interview Service user film. Conference presentation	The usefulness is in that It builds on what is already known about what each individual brings to the research and how this is shared but it also adds fresh knowledge about the bringing together of not only individuals but their beliefs, perspectives, stories, goals, behaviours and readiness to change, when brought together collectively can have provide an added dimension to the quality of the learning experience.
Shared learning experience	Celebratory event presentation. Interviews Article in BackCare members bulletin Masterclass presentation	The shared learning experience confirms some of the existing elements of good practice around interprofessional learning and group learning.
Co-learning partnership	A range of evidence is available to support the concept of the co-learning partnership	This study confirms that the concept of co-learning with service users and healthcare professionals can be planned with the service user experience in mind to enhance their experience of being involved in a co-learning capacity.

Table 10. Co-learning model; components, data sources and contribution to knowledge

8.2   Relating the model to the wider context

This research began when a group of individuals living with chronic back pain were brought together to work with a research team in a learning initiative. They joined clinical and administrative staff from their general practice in designing improvements in the quality of care for people with back pain, focusing on changes which were important to patients. These individuals, called patient representatives, were selected to participate because of their experience of back pain and they were nurtured throughout their service user involvement journey. Adopting an advisory role at the start, they progressed to collaborative working with practices which then culminated in patient-led improvement activities manifested as personal narratives and enactments in film, using role play, about the primary care management of back pain. In partnership, patient representatives and health care professionals shared the findings of the study through a variety of approaches including conference presentations and posters, academic journals and newsletters, film and the internet. That was the LIMBIC project.

The LIMBIC study illustrated several examples of good practice in service user involvement in research which were already known. These include the motivating factors for engaging in research as a service user (Fischer and Ereaut 2012; Cotterell et al. 2008; Tarpey 2006), the importance attributed to the mutual support that can be gained from working in a group (Staley 2012; McKeown et al. 2012; National Institute for Health Research 2012a; Quinlan and Robertson 2010; Hall 2009; Barnard et al. 2005), the approach towards learning and the structure of the learning environment (Fischer and Ereaut 2012; Greenhalgh et al. 2011) and the attitudes and values of the research team and other co-learners (General Social Care Council 2012; European Patients' Forum 2008; Staley 2009; Thornton et al. 2003; Crawford et al. 2002). In some ways the LIMBIC project emerged as an exemplar in service user involvement (Carr et al. 2012).

Reporting of contextual factors is important in service user involvement studies in order to be able to understand the links between context and process to achieve a given outcome (Staley 2012; Morrow et al. 2012; Stanisewska et al. 2011a; Brett et al. 2010). Figure 33 illustrates the contextual factors and the processes of

involvement used in this study which led to the outcomes both in this study and the LIMBIC project.

Service users in this study were well supported in a role for which they were well prepared and they acknowledged this as a contributory factor to their experience of involvement. They appreciated that the environment for learning and for working with their co-learner colleagues from practice teams was conducive to their role and to their task. Participants complemented one another in their contributions to develop partnerships for working together which they valued as unique and rewarding.

Context
- Preparation
- Expectation
- Information and support
- Environment

Process
- Working in partnership
- Recruitment process
- Learning together
- Improvement learning

Outcome
- A model for co-learning
- User focussed service improvements
- Changed attitudes and beliefs
- Models for quality improvement
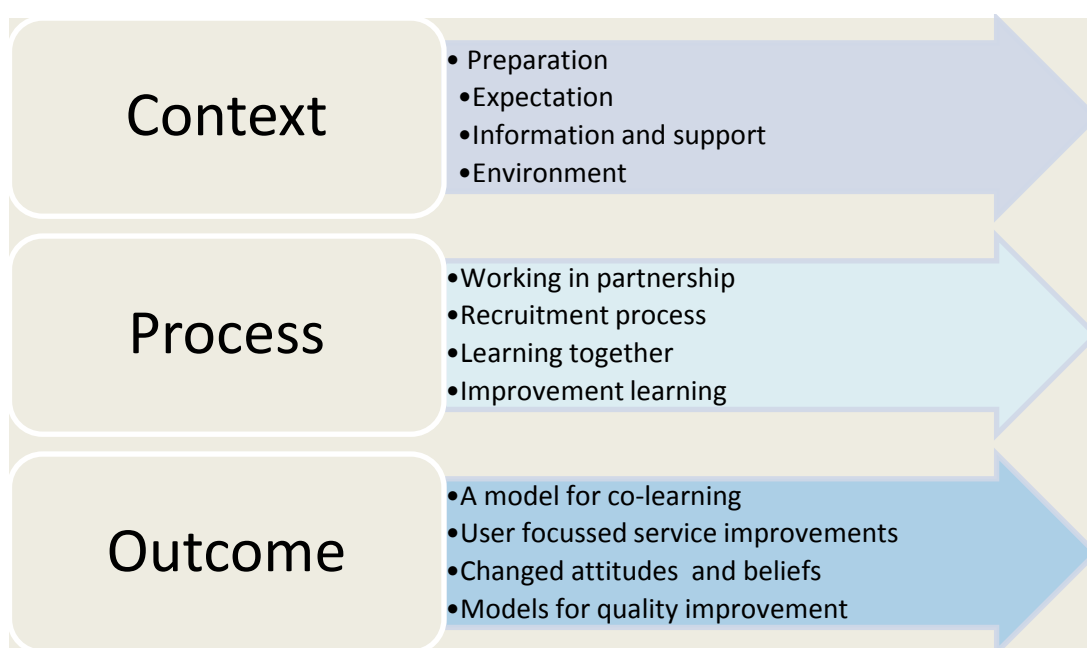
Figure 33. Linking context and process to outcome

The following discussion will explore how the findings that have been shown in this study relate to the wider literature. I have drawn on my experience of working as the project manager and researcher on the LIMBIC project, to enhance this discussion and to add another perspective to interpretation of the findings of this study

(Holloway and Brown 2012). Throughout this study, I consciously maintained a reflexive approach; a constant awareness of the influence I might have had upon all aspects of the research process and the influences which the research might have made upon my thoughts, decisions and actions. Conscious of the potential research bias that I bring as the researcher for my own study and the on-going interpretation of the findings, I retain a reflexive approach to attempt to maintain research rigour (Barnes and Cotterell 2012; Morrow et al. 2012; Malterud 2001; Piantanida and Garman 1999).

8.2.1 Movements in the field of inquiry

During this current study, developments in the literature around service user involvement were about the clear need for improvements in the quality of undertaking and reporting research involving service users. Another shift in this field of inquiry has been about the extent to which the professionalisation of service users strips them of their lay status and questions whether this means that, as credible experts, they can remain representative of the public or representative of a typical patient. The debate about whether power is shared or transferred to the service user is on-going in the literature about the importance of the partnership approach to service user involvement. A new question that has emerged asks who benefits from service user involvement as researchers seem to differ in their views about this when service user feedback is sometimes ignored. New definitions are appearing about the role of the service user as they become teachers, leaders and, as this study shows, co-learners. These new definitions position the body of evidence ready to move into new territory as researchers, health care professionals and policy makers recognise the breadth and depth of the potential impact of service user involvement on the quality of health care. The co-learner role sits within this evidence and is supported by the data from this study to bring this new direction for service user involvement to centre stage. This study contributes to a new movement in this field of inquiry about the opportunities for service user involvement.

8.2.2 *Quality of reporting service user involvement*

Researchers express frustration that studies involving service users are difficult to locate through traditional search mechanisms due to the way in which studies are being reported. Suggestions are being made for using quality standards, checklists and systematic approaches for reporting studies about service user involvement (Shippee et al. 2013; Equator 2013; Gutteridge and Dobbins 2012; Boote et al. 2011; Staniszewska et al. 2011a; McKeown et al. 2010; Greenhalgh 2009; Green 2007). Implementation of these various recommendations should improve the quality and reporting of studies involving service users allowing future researchers to undertake more comprehensive and inclusive literature searches and so identify the relevant literature for their studies.

The quality of reporting service user involvement studies can be improved if the impact of service user involvement is clear. The impact of service user involvement can only be explored if the aim of involving service users is clear. A competently articulated aim for involving service users contributes to their understanding of the project, their reason for being involved and therefore what they might expect from their experience of engagement. Clear aims for involving service users on the impact of research can help increase the economic and societal impact of the research (Research Councils UK 2010b). Sometimes, studies may fail to exhibit clear aims for involving service users which can lead to lost opportunities and unmet expectations (Greenhalgh et al. 2011; Williamson et al. 2010; Stewart 2008; Hodge 2005). Well managed expectations on the other hand are influenced by the clear articulation of the aim of involving service users in research studies (Kreis et al. 2012; Armstrong et al. 2013; Barber et al. 2011b; Lowes et al. 2010; Stewart 2008; Baxter et al. 2001).

The evidence base has increased showing that research involving service users makes the research more relevant to the people for whom it is designed (INVOLVE 2013; Staniszewska 2011b; Research Councils UK 2010a; Cotterell et al. 2008; European Patients Forum 2008). There is agreement that research funders are now more supportive of service user involvement and explicitly require service user involvement in their bidding processes.

Improved evidence now shows that service user involvement in research has an impact on the service users (INVOLVE 2013; Morrow et al. 2012; Staley 2009; Wyatt et al. 2008). Some studies which have illuminated the service user experience differently reflect critically upon the processes used to facilitate their involvement and these can bring equally important learning (Lauckner et al. 2012; Staniszewska et al. 2011b; Barber et al. 2011b; Williamson et al. 2010; Brett et al. 2010; Fudge et al. 2007). Experts in service user involvement research promote the reporting of all findings including those which reflect critically. For some patient representatives in this study who described aspects of their experience in terms of regret and unmet expectations, this did not prevent them from being proactive in their contribution, for example engaging in quality improvement work with the practice teams and disseminating the project findings. It is important that we learn about the processes which might influence uncomfortable experiences for service users in order that improvements can be effected.

8.2.3   *The beneficiaries of service user involvement*

Researchers do not always make it clear whether service user involvement is aimed at benefitting researchers or patients. Some researchers may wish to engage with service users to gain service user support for their decisions, whereas others may seek to be challenged by service users in their decisions (Thompson et al. 2012; Lehoux et al. 2012a). This illustrates the importance of managing structures and processes for involving service users to ensure their views are heard and acted upon (Armstrong et al. 2013) and their role is clear to everyone.

This study showed that not everybody who engaged as patient representatives benefitted from their engagement and some people felt a sense of frustration when they saw lost opportunities for learning or when they did not learn about their condition as expected. For some service users, the prospect of participating in research might seem irrelevant to them and they might feel it is beyond their individual capacity (Fisher 2002). Supporting them in managing their expectations is a fundamental part of improving this process.

Having multiple service users on improvement teams, and diversity within the groups, is beneficial to the group work and is preferred by some service users (Ling

et al. 2012; Lowes et al. 2010). Van de Bovenkamp and Zuiderent-Jerak (2013) suggest a more targeted participation approach where service users need not be present for every single health care decision as opposed to an ideological one. The opportunities for older people to draw on their experiences and engage in participatory action research has enabled communities to initiate change through research (Marlett and Emes 2010). In concluding that it was not necessarily appropriate to involve service users in guideline development they suggested a "more elegant version of democratic patienthood" (van de Bovenkamp and Zuiderent-Jerak 2013).

8.2.4 *Representativeness of the credible expert*

The debate about representativeness of lay people who become experts has gained further momentum with some researchers arguing that the service user as credible expert is a paradox and that professionalisation of service users leads to them losing their focus on what is important for patients (El Enany et al. 2013). This debate challenges the perceived altered status of the professionalised service user. As a result of being involved in research about interprofessional education service users inevitably become educated and this might evolve to the extent where they are no longer 'lay' but semi-experts. This could be seen as a positive outcome if the service users become confident enough to enter into the discussion in the world of academia or research, but this places a value judgement on why they were recruited in the first place. When service users lose their lay status it could be argued that our expectations of them should change. The purpose of service user involvement might be primarily to exert their influence as patients on the research, but in doing so their level of understanding is raised. Therefore as a consequence of their involvement they are turned into quasi-academics, their perspective is no longer lay and they have become professionalised (El Enany et al. 2013; Staley 2013; Lehoux et al. 2012a; Lehoux et al. 2012b; Ives et al. 2012; Martin 2008). This might then bring them into a way of seeing the world as an academic. Ives et al. (2012) suggest that this professionalisation paradox indicates the need for researchers and health professionals to rethink service user involvement.

Service users might even start out as credible experts in their area of experience, for example back pain, and can therefore provide advice to the team as occurred in this study. They can also be required to assert their beliefs and articulate their expectations for the research, also shown in this study.

In contrast to the professionalised service user, Lehoux et al. (2012a) intentionally aimed to recruit service users who were not only neutral in their background knowledge but disinterested in genetics in their study. They found that attempting to dissociate the service user opinion from the person and the complexity of the background brought by each individual service user to the study was irrelevant and did not support the principles of service user involvement.

In this current study, patient representatives were credible experts in that they had experience of accessing back pain services from primary care and the language they used to articulate their clinical condition was similar to that of the health care professionals – they were professionalised in their use of language. As a consequence of their engagement in the study, they gained further knowledge about the way in which general practice worked, they learnt about how commissioning health services worked and they learnt about the educational approach that was used in this study. This further knowledge added to their credibility as individuals when they delivered presentations to groups of healthcare professionals. They were no longer lay, but they were still people who had experience of accessing services for their back pain. The argument about professionalisation of service users is therefore context dependent.

8.2.5   *Partnership and power sharing*

Service user involvement in the future is predicted to bring about a shift in power from professionals to a more equal partnership (General Social Care Council 2012, p.8). It takes courage on the part of the research team or health care professionals to allow service users to take control, but this leap of faith can lead to a difference being made as a result of partnership working (McKeown et al. 2010; Godfrey 2004; Beresford and Wallcraft 1997). Power sharing, or a shift in the balance of power, as this study showed, can contribute to the achievement of the goals and attitudinal

change. Others have demonstrated similar findings (Boote et al. 2011; Renedo and Marston 2011; Lindenmeyer et al. 2007; Tritter and McCallum 2006; Coulter 2006).

Partnerships can be most influential at grass roots level when service users contribute to patient information resources, enhance access to services, and improve the care environment (Attree et al. 2011; Pandya 2010). For future health care provision, a model being promoted for Clinical Commissioning Groups in the UK focuses on involving patients as partners in evaluating and improving care (National Institute for Health Research Central Commissioning Facility 2013; Dawda et al. 2010) - a model similar to that which was central to the LIMBIC project. Tritter and Koivusalo (2013) however, criticise the new arrangements because they downgrade the place of service user involvement and equate patient involvement to patient choice. Shifting power requires a different kind of relationship, in which health care professionals work in partnership with service users to sustain healthy lives (Parston and Kippin 2010). This is happening in the world around us with devolved responsibilities for service provision including financial responsibilities, in government and in health and where patients are increasingly being expected to take responsibility for their own health (Morrow et al. 2012).

The partnership model differs very much from what currently occurs in clinical practice. Given the central role of the doctor-patient encounter in health care, the doctor-patient dynamic needs to change to reflect that there are two parties engaging with separate goals (Fischer and Ereaut 2012). In this current study, the doctor-patient dynamic *did* change and this created an immediate impact on the progression of change within the project. This study showed that doctors and patients together can influence patient care and practice procedures when adequate time is allocated. Patient representatives recognised when change was required and that this might mean removing barriers, creating the right setting, and agreeing ground rules, all of which require good facilitation. They also recognised that to enable this process, a partnership was required. The partnership approach can be a challenge in current UK health service delivery where an historical, paternalistic approach sometimes prevails (Spencer et al. 2011).

The elements of partnership working which were important to the experience of the service users were around the processes used for recruiting service users, their readiness to change when improvements were planned, the importance to them of being provided the time to be listened to, and the forming of partnerships to work together.

When participants feel equal to one another and treat each other equally, a setting for honest and open dialogue can be established which can foster creative thinking and innovation. Integration of researchers and participants as equal partners at each stage of the project is an important outcome in the co-learning relationship (Chirewa 2012; European Patients' Forum 2008).

There was a shift from viewing the patient as a recipient of services, to working in partnership with them. This has been shown in other research which involves health service users (National Institute for Health Research Central Commissioning Facility 2013; Thompson et al. 2012; Ling et al. 2012; TwoCan Associates 2011; Frankham 2009).

There is strong evidence that service user involvement in health and social care professional education has short term benefits for all involved (Spencer et al. 2011). Health and social care professionals are increasingly embracing and embedding service user involvement in their work in order to influence change, but there is still a long way to go. We only need to look to the frequently cited paper by Arnstein (1969) to realise that this argument, about where the power should lie, remains the issue. This is changing (Tritter and McCallum 2006; Tew et al. 2004) however, and if we can improve the way we work with service users by acknowledging the messages from this research and that of others we can move some way towards that partnership goal.

8.3   Strengthening the evidence base

The findings from this study which add to the current evidence base for service user involvement are now discussed.

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8.3.1   *Clarifying the aim for involving service users*

Failure to clearly communicate the aim of involving service users can lead to feelings of frustration on the part of the service users and, as a result, they might fail to fully participate or disengage completely (Hogg 2007; Henwood 2007; Carrick et al. 2001). If the aim of involving service users in a project is not effectively communicated, this may be an error of judgement or an oversight, or it may occur because the aim of involving service users is not always clear, even to the project team (Vale et al. 2012; Social Care Institute for Excellence 2012). It might be the case that the aims of involving service users are not shared with participants because there is a hidden agenda, or there might not be an explicit aim for involving service users. Armstrong (2013) has indicated that studies defining a clear aim for involving service users are scarce and this causes concern because this will lead to service users entering studies without knowing how they may be expected to influence the study.

Most of the patient representatives in this study understood both the aims of the wider study and the aims for their involvement. These aims were clearly communicated both verbally and in the supporting written information that was provided for them and clarified in their group meetings. This information was, however, provided after the patient representatives had been identified by their practice team as eligible for recruitment into the study. Most of the patient representatives had clear expectations, for example about the ways in which they were expected to influence the practice team improvement projects. Patient representatives in this study knew to expect that they might be asked to get involved in defining topics, developing measures and interpreting results in quality improvement activities. However, whilst examples of how service users might be involved were articulated by the research team, the *purpose* of service user involvement in the studies was *not* stated by the funding body of the overall award scheme, nor were methods of service user involvement suggested.

This funding body does have a strong history of involving service users but in this particular scheme, it seemed that award holders were expected to develop their

own ways of working with service users (Ling et al. 2012; Fischer and Ereaut 2012; Spencer et al. 2011; Health Foundation 2007; Leatherman and Sutherland 2007; Ellins and Coulter 2005).

8.3.2 Supporting service users

Evidence about the importance of support for service users and recruiting service users remains largely unchanged. Carefully tailored training and support for service users has proved effective (Caldon et al. 2012; Morrow et al. 2012; Greenhalgh et al. 2011; Staley 2009; Cotterell et al. 2008; Glynn et al. 2008; Downe et al. 2007; Smith et al. 2006). In the wider award scheme to which the LIMBIC project belonged, high quality and continued support helped participants develop a sound understanding of the principles of their projects and their role in influencing its process and outcome (Ling et al. 2012). Information packs for service users and staff is known to be helpful to them (INVOLVE 2012; General Social Care Council 2012; Staley et al. 2012; Saunders et al. 2007) but it should be recognised that service users will have different levels of information needs (Glenton 2002).

Strategies for communicating which were adopted in the LIMBIC project included one of maintaining contact with co-learners in between the monthly workshops and this took place using the project wiki as well as through email and phone contact. The use of a wiki (see Glossary) as a tool to support learning was a relatively new concept at the time of the workshops in 2008 and the use of a wiki to support service users in their role was then, and to some extent even now, quite rare (Carr et al. 2012; Cooner cited in Higher Education Academy 2011; Morley 2011; Pulman et al. 2009). This innovative social medium approach engaged most of the patient representatives in this study equally as much as the healthcare professionals, with some reporting that they had particularly enjoyed that aspect. The wiki gave users access to the material which was used in the workshop, it allowed all the participants of the project to look at each other's improvement projects and it provided a forum for on-line communication. The wiki provided an additional route for access to information for patient representatives to support them in their understanding and in taking a participatory role in the educational initiative.

8.3.3 Recruiting service users

The process of recruiting service users has been shown to reflect significantly upon their subsequent involvement experience. Initial contact with service users, described by Morrow et al. (2012, p60) as "making connections," holds the key to our understanding of their experience of engagement in research and needs careful planning. Information and support is part of a well-managed recruitment approach. Early negotiation about roles gives way for mutual respect and an active relationship, and establishes the process of two-way communication (Caldon et al. 2010; Boote et al. 2002). A recent systematic review revealed the co-learning process as one of four integral components of service user engagement in research (Shippee at al. 2013). The emphasis on co-learning was found to be around recognising that both researchers and service users required training to understand their roles in working together.

In this study, patient representatives who were recruited late into the LIMBIC project indicated that they would have preferred to have joined the project at the start and some expressed feelings of regret about this. We already know that involving service users early in a project is important in helping them to better understand the project aims, and that recruiting too late can affect the impact of their involvement (Armstrong et al. 2013; Staley et al. 2012; Ling et al. 2012; Pandya 2010; Caldon et al. 2010; Foot and Ross 2010; Staley 2009; Baxter et al. 2001). Boote et al. (2010) suggest involving service users in making recommendations about the timing of approaching participants about getting involved. We also know that the impact of service user involvement is optimised when they are involved throughout the entire project (Staley 2009; Walter et al. 2003). A new finding shown in this study was that the timing of recruiting service users can also play an important part in their experience of being involved.

The expressions of regret made by some patient representatives about not being there at the start of the LIMBIC project, is a very important finding in this study. Those patient representatives, who joined the project late, had missed some of the shared learning opportunities which had occurred earlier in the project. Not being involved in telling their stories, because of joining the project late influenced their initial experiences. Not knowing as much as the others, made them feel different.

Disadvantaged in this way, these service users might have felt less valued compared to other service users in the study. Others have also shown the timing of engaging with service users to be important. Joint learning with service users and researchers at an early stage might have increased opportunities for service users to influence the research design or its accessibility (Barber et al. 2011b).

In this study the process for recruiting service users might have been handled more considerately. Had all the patient representatives been offered introductory advice and support together at the same time and at the start of the project, there might have been different outcomes. Different people might have been recruited to the role of patient representative. There might have been different inputs from the patient representatives leading to different improvement projects being undertaken by practice teams and there might have been different levels of met expectations and overall satisfaction for the patient representatives. The drive to achieve the target number of patient representatives, which was a goal for the LIMBIC project, might have overpowered the task of supporting the service users through the initial stages of their user involvement role. In such situations, where it is unavoidable that some service users are latecomers to a project, it might be worthwhile developing an additional support strategy to enhance their integration into the group. Alternatively, in the light of the findings of this study, it could be argued that engaging service users to start at different times should be avoided altogether.

Another important consideration to make in recruiting service users is the diversity of needs of service users, for example, the requirements for people who have difficulties with learning, and those who struggle in social settings. A lack of evidence in the literature of research involving service users with special needs indicates there is more work required to support those with special needs in service user involvement initiatives (Katz et al. 2012; Rooks et al. 2012; National Institute for Health Research/Mental Health Research Network 2012; Fudge et al. 2007; Abma 2005). Some researchers have made efforts to recruit service users who are best matched to the research topic and who might require additional support due to their capabilities, for example, people with long term health conditions, but such examples are rare (Rhodes et al. 2002).

Defining and managing expectations are part of a considered recruitment process. Expectations were well managed for the patient representatives in this study in the following ways. First, the wealth of experience of the LIMBIC project team in the area of service user involvement, and the carefully crafted project plan which articulated the purpose of involving service users, contributed towards creating the setting for true engagement to occur. Second, the overwhelming success of the involvement of service users across all projects in the Health Foundation award scheme seemed to take the award-holder teams by surprise (Ling et al. 2012). This might have been because the service users or the research teams or the funding body did not know what they were supposed to expect as a consequence of involving service users. It might have been the case that the impact of service user involvement was supported, encouraged, visible and genuine.

Providing participants with information to support their understanding of a co-learning initiative can help them understand what they might expect to experience or to gain from engaging in a project and this can be offered at different levels of complexity (Kries et al. 2012; Glenton 2002). In this study, whilst patient representatives described similar experiences, there were also many differences and this might have been influenced by the extent to which their expectations were met. Whilst good practice suggests that expectations should be made clear at the start (General Social Care Council 2012; Staley et al. 2012; Greenhalgh et al. 2011), because peoples' experiences of involvement can be different, it is necessary for researchers to prepare for meeting different levels of expectation. This creates further challenges for researchers who need to advise people about what to expect or anticipate from their engagement in a project. Whilst all of the patient representatives in this study were provided with written information about the study, its purpose and the purpose of involving service users, there was no way of knowing how many of them read the information they were given. This may be relevant in the context of those who reported that their expectations were not met.

The importance of clarity and transparency in outlining the service user role, whilst acknowledging that some service users might need more support than others, are revealed by this study as crucial components for supporting service users in managing their realistic expectations. Some people might not work well in meetings

and might wish to be involved in different ways (INVOLVE 2010; Henwood 2007). Researchers also need to involve a diverse range of users, which can be an added challenge when recruiting (Staley 2010; McCormick et al. 2004).

Despite careful planning, some service user initiatives can take directions that were not planned at the outset (Downe et al. 2007). These directions could be unexpected in that they lead to research ideas being abandoned (Boote et al. 2012). Some patient representatives in this study commented that they did not know what to expect, implying that expectations were not made clear to them at the outset. These participants may have missed some of the early discussions about the role of the patient representative. The provision of written information may therefore not be enough to support them in their role.

Many service users volunteer because they wish to influence and improve services for patients in the future (Cook 2012; Barber et al. 2011b; Williamson et al. 2010; Cotterell et al. 2008; Fudge et al. 2007). If they see this happen as a result of their involvement, their expectations are more likely to be fulfilled (Staniszewska et al. 2011b). Likewise, if this does not happen, within the lifetime of the project, this might mean that they are left with unmet expectations or a disappointing memory of their experience of involvement. Whichever is the case, as this study has shown, an open dialogue about the study aims, especially in relation to the purpose of service user involvement, helps to contribute towards a better understanding of the purpose of the research and to their subsequent experience of user involvement.

8.4   Becoming a co-learner

A challenge for researchers in clarifying the aims of a co-learning initiative is that people respond differently to different learning approaches (Atherton 2011; Fry et al. 2009). The educational initiative related to this study did have an intended element of uncertainty whereby the research team wished to be responsive to the learners' needs in their design and delivery of content of the workshops. An action learning methodology approach to teaching was used in which participants were supported to identify their own learning needs, to share their learning with peers and use reflective approaches (Chirewa 2012; Jinks et al. 2009; Cox and Young 1999). This

made it difficult for the research team to articulate what participants could expect, especially regarding the learning experience. For some of the patient representatives in the wider LIMBIC study, this abstract notion of learning was acceptable, but for others, it was a difficult concept to embrace. Some participants welcomed the unexpected aspect of the workshop content each week, while others struggled to grasp an understanding. A few of the patient representatives in this study described how they had not understood a lot of the workshop content and the structure of the workshop sessions had not suited their preferred learning style. Others seemed to adapt more easily to the unfamiliar setting and the learning approaches which were offered. People differ in their acceptance of and preference for styles and approaches to learning or engagement and so it is important to explain these concepts at the start of a study (Richardson 2011). In doing this, the research team takes the risk of providing too much information and putting people off at the very start but this may be a risk worth taking if it is offset against the potential for poorly informed service users.

Each service user brings their individual beliefs, values and everyday experiences (Fotaki 2011). The experiential knowledge of service users is a source of advice that cannot be substituted by professional knowledge and so makes the service user contribution a legitimate one (Lehoux et al. 2012a; Glenton 2002).

Patient representatives in this study recognised that the non-hierarchical approach helped towards collaborative working in the learning environment and it was very different from the usual dynamic in the clinical encounter in the health setting. The experience for most of the people who were involved in this study was one of a shared journey where co-learning and co-constructing created new meanings. Whilst it is acknowledged that the presence of hierarchical structures in settings with health care professionals and service users can constrain dialogue (Renedo and Marstin 2011), others have pointed to the counter effect of creating and maintaining a non-hierarchical structure (Armstrong et al. 2013; Sullivan et al. 2001). Service users on the level playing field are expected to engage confidently in debate to defend their opinions which might not be easy for them. In this study, the co-learning environment that was created allowed this to occur and patient

representatives were supported and encouraged to lead with their points of view, their stories and their knowledge.

Whilst many examples of service user involvement can be found in health education environments, examples of service users working with the medical profession are scarce (Spencer et al. 2011). Examples that are found tend to be the result of work by individual champions. Patient representatives in this study described their position as if they felt they were in a privileged place, not usually accessible for those outside the primary care setting. In this way they felt special and the experience felt important to them. This might have been because they were shown respect and they were told that they were valued for their views, their knowledge and their experience. For them, this had not happened before in relation to their enduring clinical condition which tells us that they are used to something different. In their clinical encounters some of them reported they were not listened to and there was no sense of equality in their relationship with their doctor. A hierarchy hindered dialogue and suppressed the potential for open and shared decision-making. In this study, the purpose and the setting of the co-learning environment were different to the clinical encounter, like the same actors on a different stage. Being invited to walk onto the stage to become part of being behind the scenes was a significant step for the patient representatives.

8.4.1   Co-production as part of being a co-learner

The co-learner role of the service user working alongside healthcare professionals led to co-production in the context of quality improvement. The patient representatives and practice teams developed improvements in practice as a consequence of their learning together. The conditions for working together and learning together were evidence-based and responded to an identified need (Breen et al. 2007). Many of the important features of co-learning were optimised due to the preparation and planning that had taken place, but there were also some weaknesses in these plans which influenced the patient representatives' experiences such as the timing of recruitment of patient representatives.

In this study, the focus on developing and maintaining good communication led to a changed relationship, to one in which openness and equality became the norm. It is considered good practice in quality improvement in clinical communities to establish shared norms of conduct where members of the community become united by a common purpose to learn or share knowledge and take responsibility for achieving their aims (Aveling 2012; Dawda et al. 2010; Baxter et al. 2001; Lave and Wenger 1998). Holding this community together is achieved by involving patients as well as healthcare professionals, working across disciplinary boundaries and sharing experiences. Trust, honesty and respect prevailed amongst the individuals who were engaged together. These aspects have also been reported in other studies (Staley et al. 2012; Barber et al. 2011b; Caldon et al. 2010; Boote et al. 2002). Patient representatives felt that they had the freedom to speak. A source of untapped knowledge (Saunders et al. 2007), in collaboration with the project team, they co-created a facilitative, respectful learning environment.

The patient representatives in this study shared their experiences about their engagement with the practice teams, their views on the presentations in the workshops and their experiences of their medical condition. Previous work has shown that peer support enhances learning and creates fruitful working relationships (Barber et al. 2011b; Staley 2009; Rhodes et al. 2002). This collaborative approach by the patient representatives contributed to their experience by helping to provide an environment where open discussion and sharing of opinions formed part of the co-learning culture. This led to the group having the confidence to take lead positions later in the project such as in making the film, speaking at conferences and sharing their opinions with clinically qualified co-learners.

Engaging service users in partnership with professionals creates one of the essential components of reform (Boyle and Harris 2010). Service users who choose to engage in such ways in health services probably do so because they wish to stop the cycle of inconsistent and inappropriate utilisation of health care they have experienced themselves. The patient representatives in this study wanted to take control of maintaining their health, so they became co-creators of their own health management strategy and they wanted to share their important new learning

with others. Recognition of the value of their contribution evolved over time. Their user involvement role shifted to one of co-production. In the context of co-production, instead of just being consulted, service users become equal partners and co-creators of service change (Social Care Institute for Excellence 2012). In some service user involvement initiatives, the role of service user is one of advisor where they are consulted for their opinions in meetings, have their views documented and their ideas progressed through the organisation or the project over a period of time (Henwood 2007). In this study the involvement was more than that. It was visible and it was current. It was active and not passive. Service users had an important role to play and everyone's contribution counted. Most of them engaged as partners in working together; the insiders with the outsiders (Bartunek and Louis 1996) - service users worked alongside service providers. The continuing partnership was about a process of working together towards a goal of mutual benefit through discussion and negotiation.

8.4.2 Patients as leaders

Service users who engage in research or educational initiatives should be prepared for the possibility of changes in relationships, perspectives, and behaviours (Foot and Ross 2010; Nathan et al. 2006). Educators need to overcome deep habits and new levels of co-operation are needed (Batalden et al. 2009). Telling stories can be "inherently emotionally charged" (Greenhalgh et al. 2011 p73) and can yield rich material for analysis (Blickem and Priyadharshini 2007; Ong and Hooper 2003). In this current study, the need for the patient representatives to tell their story permitted depth of reflection in the broader context and they observed and they experienced a shift in behaviours, beliefs and attitudes. Those behaviours were about how GPs communicated with their patients, they were about learning that GPs did care, and they were about how people expected that back pain should be managed. To quote Ling et al. (2012, p.29) "There was a quantum shift in attitudes, understanding and abilities." The act of engaging gives us an insight which might otherwise not be revealed.

There were changed behaviours illustrated by changes in clinical practice, changes in approaches to self-management of back pain and, for the patient representatives,

the emotional impact of seeing change happen as a result of their involvement. Seeing GPs change their attitudes to managing back pain, as a result of what they had learnt, and knowing that they, the patient representatives, had influenced this, led to the patient representatives feeling that they were part of the learning. Being part of the learning led to patient representatives getting what they wanted; they saw change happen and they knew the changes they saw could lead to a better patient experience for people in the future who might seek health advice from their GP for back pain. Patient involvement in this study was a powerful motivator of behaviour change among clinicians. The attitudinal shift which occurred is seen as a goal for quality improvement as it forms the basis for transformational shifts in the delivery of care (Ling et al. 2012).

This study found that a willingness to learn, a willingness to change the way people think about things and what they believe, are all aspects of the culture which support the learning experience. Most of the patient representatives showed strong commitment to the project through their continuous and regular attendance at the workshops, especially compared to some of the healthcare professionals who failed to attend all the workshops. This was the time when the patient representatives began to see that they had the potential to take more of a leading role in relation to meeting the goals of the project. They began to see themselves as more committed to the goals of the project than their health professional co-learning colleagues. This study has illustrated the importance of recognising the potential of the leadership role of service users as others have also suggested (Goodwin et al. 2013; Morrow et al. 2012, p.xii). The principle of engaging service users in the design of services using the model of experience-based co-design (Bate and Robert 2006) brings a deeper more rewarding experience and results of service user involvement which are more sustainable (King's Fund 2013).

A new finding in this study shows the patient representatives as collaborators on improvement projects and as leaders implementing and disseminating the research findings. Patient representatives were not overwhelmed by the concept of collaborating in partnership to effect change. A major lesson that was learnt is that there is no need to fear that service users do not have the capacity to lead. Patient representatives were invited to bring their ideas to the table about improving back

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pain services. They were trusted to work together with practice teams and they were given the freedom to lead the way when it came to sharing their learning with others.

A new movement which started in the voluntary sector, promoting patients as leaders, is gaining momentum in health care. It describes the qualities of a patient leader as being similar to a strategic leader with a capacity for self-leadership, the ability to focus on solutions and a willingness to value and work with others (King's Fund 2013; Doughty and Gilbert 2012). Researchers predict seeing patient leaders working alongside health care leaders in the future to create service improvement through co-production (King's Fund 2013). This mirrors the way in which patient representatives undertook their role in this current study. The patient representatives described how they entered into a study which was not just about watching the health care professionals learn. It was about them engaging genuinely in a process which they fully understood and in which they were trusted to lead in teaching others about involving service users in service improvement, co-production and co-learning.

8.4.3 Returning to the model for co-learning

Creating a learning environment outside of the workplace and in a setting which is neutral to all the participants was valued by learners in this study. The setting for the workshops allowed for a different relationship to develop between patient representatives and health care professionals, different to that in the health provider-health recipient encounter. Fischer and Ereaut (2012) noted that for those who work in general practice, being out of the practice can create a level playing field; an observation made by the patient representatives in this study. Service users need to feel free to express themselves, and if the environment is open and participants feel safe, this is more likely to happen (Rhodes 2012; Minogue et al. 2005; Hammick et al. 2009; Fudge et al. 2007).

In this study, the setting was unlike the participants' workplace, it was unlike the clinical setting, and although it was created to function as a learning environment, it also had the features of a social occasion. There were opportunities for social

encounters and the social conditions for dialogue were created. This has also been shown in the work of McKeown et al. (2012), Brett et al. (2010) and Abma (2005). It might not always be possible to create a neutral learning environment; for practical reasons studies may need to remain situated in a clinical or educational setting but the research team should embrace its responsibility for building a supportive environment for co-learning (Morrow et al. 2012).

This study found that removing some of the barriers to productive working, for example agreeing the language, contributed to the level playing field for co-learning to occur. An environment for co-learning was created in which people respected one another for who they were, just as much as what they might represent, and this contributed to their learning experience. Setting aside differences and creating a level playing field can go some way towards making people feel safe in the environment and so prepared to engage in open discussions (Rhodes 2012; Cook 2012; Barber et al. 2011b; Tritter and McCallum 2006). Other researchers too have reflected on the importance of using a language that is easily understood by everyone when health care professionals and patient representatives work together (Boote et al. 2010 cited Staniszewska et al. 2011a; General Social Care Council 2012; Staniszewska et al. 2007; Glenton 2002). Setting ground rules at the start of a project with service users and an agreed use of a common language will enhance participant's understanding, with the caveat however that all participants adhere to the ground rules. Inevitably, when health professionals are asked to modify their language and replace medical terms with lay terms, there will be a period of adaptation where medical jargon may be used through habit (Wyatt et al. 2008; Basset et al. 2006). The identification of a nominated champion to promote the continued use of the ground rules about language will go some way towards supporting the service users in their familiarisation with the environment (Spencer et al. 2011; Saunders et al. 2007). Failure to observe ground rules might imply a lack of respect for the service users and avoidance of language containing jargon (National Centre for Involvement 2009) is a component of the right environment for co-learning.

Time is a valued resource for everyone and should not be taken for granted or compromised when listening to service users (Cook 2012; Lowes et al. 2010;

Cotterell et al. 2008; Godfrey 2004; Boote et al. 2002). In this study, protected time helped patient representatives form productive working relationships. If there had not been time allocated to developing these relationships, the project might have progressed very differently.

There is much debate about the time constraints, or perceived time constraints placed upon health professionals, on the doctor-patient encounter and theories about how and why this might be so (Frosch et al. 2012; Blickem and Priyadharshini 2007). In reporting their experiences of encounters with doctors, patient representatives in this study accepted that the time allocated for the encounter with their GP was limited. Recent research has acknowledged that allowing patients to choose their length of appointment time for example, gives patients greater responsibility for time management in the consultation (Sampson et al. 2013). The role play in the LIMBIC film showed how important it was for the patient representatives to see the small changes made to the way in which the clinical encounter was conducted because it was an outcome that was relevant to them.

In the LIMBIC project, some of the practice teams *did* increase the amount of time allocated for patients in the clinical encounter through undertaking their improvement projects which meant that their patients *did* get what they wanted. Some practice teams offered longer follow up appointment times to patients with chronic back pain; another example of patient representatives in this study seeing change happen as a result of their involvement. Patient representatives observed the changes which were put in place as a direct result of their involvement. They observed a shift in behaviour.

8.5   Potential impact on co-learning

This co-learning model is proposed as a guiding framework for health care professionals, researchers and educators for use in planning and undertaking service user involvement when their role is that of co-learner. It outlines the core features important to service users that can influence their experience. Service users who are well informed and understand their role can be expected to contribute to a study in ways that they feel comfortable and in ways that they understand can

satisfy the study aims for service user involvement. If they are well supported and nurtured through their experience this may benefit the study by drawing upon lived experiences to inform the learning of others. Study contexts will differ, not all components of the co-learning model will always be required and will not always work but this model can be adapted to the context.

The body of literature about involving service users in interprofessional learning is becoming well established with growth shown in the use of theory and terminology (Paradis and Reeves 2013; Reeves and Hean 2013). The service user as co-learner, which came out strongly in this study, embodies the interprofessional learner. As in interprofessional education, the service users and health professionals learn with, from and about each other (Hammick et al. 2009; Barr 2002). In a co-learning capacity, they also share the roles of expert and novice, teacher, and learner and these roles will change throughout the study. Together, they also apply their new knowledge and re-create knowledge. They will approach issues that are important to all of them using methods which benefit them and they will also be actively involved in deciding what to learn and how to learn. This model offers health professionals and researchers a structure for planning and delivering their service user involvement initiative which involves participants learning together.

A recent inquiry showed that quality improvement is not yet embedded in the workings of general practice in the UK (Parson et al. 2010). A cultural change is required (Coulter 2006) and commentators urge care providers to include a focus on the measures of patient experience as well as those of clinical care to drive forward overall improvements in quality of care (Patient Centred Outcomes Research Institute 2012; Parson et al. 2010). In this study, the service users' roles changed and grew over time as they became increasingly active in shaping their own involvement. As this happened, the health professionals changed the degree of importance they placed upon service user involvement and they changed their beliefs about the value of user involvement. Others too have shown changed beliefs and attitudes towards service user involvement as a result of working with service users (Mockford et al. 2012; European Patients' Forum 2008; Oliver et al. 2008; Nathan et al. 2006).

The culture is changing and examples of good practice are widespread as seen in the NHS Constitution in relation to patient involvement in research (Purvis 2012), recent changes to the standards of training in the Health and Care Professions Council (Health and Care Professions Council 2012b), and the launch of the Involvement4Access resource for promoting the recruitment of Patient Research Ambassadors (National Institute for Health Research 2012b).

Focussing on the aspects of the LIMBIC project that were unexpected or critical, or which might be framed as faults or failings, brings relevance to this discussion about factors that contribute to the service user experience when that might be about unmet expectation or regret. This study found that changing the intended approach to recruitment of service users, the perceived inadequate articulation of the purpose of service user involvement in the context of the study and the perceived lack of a strategy for managing the expectations of service user participants were all relevant to the experience of the service users.

The purpose of this study was to gain new knowledge of the service user experience by exploring the experience of health service users engaged in a specific research project. It explored the experience of a group of patient representatives in their co-learning role. The findings were presented as themes which yielded insight and held within them several key concepts which cohere to form a model for future successful co-learning. A model has evolved through on-going analysis of the study findings and their interpretations (Richardson et al. in Denzin and Lincoln 2000), and is proposed as a framework for a co-learning partnership which could be applied in other health care, research and education settings. The model is grounded in the data from this study and offers sound proposals for others who plan to work with service users and it highlights shortfalls which could be avoided to optimise the service user experience.

This robust research study engaged with people who endured difficulties in their healthcare experiences and who wanted to make a difference for others. Outlining a clear purpose meant this study achieved what it set out to do. The question was not about involving people in research or about what impact they had on the outcome.

Those questions can only be asked when we know *why* we choose to engage with service users in the first place. This research wanted to know what people go through when they get involved as service users. This research asked that question, "How did it make you feel?" and service users described the good, the fair and the poor, the frustration and delight, the regret and the anger, the togetherness and the surprise. They learnt, they benefitted, they felt equal and they were valued. They were outsider and insider, and they began to see things in a different light. They tried hard, and sometimes felt inadequate, and one of the most important things for them was the fact that they were listened to. Sharing a learning journey with colleagues from their practice team and the outcomes of their endeavours led to self-development, practice improvement and co-production of new knowledge.

The tools used to gain these insights were interviews, research records, learning material and a pragmatic approach towards exploring the service user experience, analysing a variety of types of data through trying various methods and exploring patient representatives' experiences through semi-structured interviews. Specifically designed strategies for data collection, data management and data analysis guided the research processes.

These findings have been presented to academic colleagues and healthcare professionals, discussed and re-evaluated (see Appendix 1). They are due to be published in the academic literature, shared with service user and healthcare organisations and used in educating healthcare professionals. The collective learning that has been achieved will contribute to the widening literature about service user involvement. This research has carved a niche in that body of work by presenting new findings which illustrate that service users require clarity about their role and efforts need to be made in recruiting and preparing them for their experience of service user involvement. They also need on-going support in their partnership role.

8.5.1   *What difference did this study make?*

The expertise of the research team in facilitating user involvement was crucial in crafting a co-learning environment where service users could contribute in ways

they felt comfortable leading to the co-production of changed practices in primary care. This study provides insight into the experience of the patient representatives in their co-learner role. It directs us to a view of co-learners in action. It shows people who were equal to one another working together to shared goals which included service improvements.

In relation to the process of user involvement it shows that recruiting service users to start their journey of involvement at different times from each other led to feelings of regret. This showed how important it is to make sure that all service users enter a project at the same time as their co-learning colleagues. Recruitment therefore needs careful planning and changes to recruitment strategies should be considered with service users in mind.

We are now more aware of the need to understand each other's expectations for participation in order to avoid unrealistic expectations being developed.

This chapter has offered a discussion about the relevance of the research findings for researchers, educators and practitioners when working with service users in an involvement role. Service user involvement is more important today than ever before because evidence of its benefits to patients, to the health care system and to health care professionals is convincing and indisputable (INVOLVE 2013; Barnes and Cotterell 2012; Hill 2011; Williamson 2012; Morrow et al. 2012; Greenhalgh et al. 2011). Understanding what is important to service users will help health care professionals, educators and researchers in their important role of supporting service users in their involvement role.

9. Conclusion

This chapter reflects upon the design, the undertaking and the outcomes of this study and the contribution to new knowledge that has been achieved. It explores the extent to which the research question was adequately addressed and the research aims were achieved. Recommendations are made based upon these new findings which might be applied to similar studies and this includes a new model for co-learning. A discussion of the limitations includes reflections on what might be done differently if this study were to be repeated. This chapter concludes with reflective remarks about where this study fits in the wider context of service user involvement in health research and health education and health care.

Conclusions that can be drawn are around new learning for the health and social care sector about undertaking research with service users in a co-learning role. New knowledge has been gained about recruitment of service users, the need to provide adequate time for planning the service user approach, the preparation of the environment and the importance of agreed, effective communication processes. A model for co-learning resulted from the analysis of the findings of this study and the application of this model in practice could lead to the engagement of service users in co-learning studies which better meet their expectations.

This study has contributed to the current knowledge base because we now know that when service users are provided with good support, have clear information about their role and the purpose of their involvement, that their experience can be a good one. When the goals for service user involvement and their role in the study are not clear their experience might not be so positive. When service users are involved in interprofessional education, co-learning becomes a key feature of their experience and can help to drive change forward. When service users in the same project start their engagement at different times they can feel regret when opportunities have been missed.

9.1 Summary of the findings from this study

This study has shown that service users who are invited to engage in education evaluation with health professionals can bring new ideas and new thinking, grounded in their personal experiences of health care. When provided with a well-designed system of support for carrying out their role, service users can find their experience to be enjoyable and rewarding. When expectations or the purpose of their involvement are not clear, service users can experience frustration and they might engage in different ways.

Researchers can learn from this study about some of the ways in which service users experience being involved in the world of health care research. For example, patient representatives expressed discomfort being involved in discussions with practice teams other than their own, when they had been recruited from elsewhere. They felt sorry that they were unable to get fully involved in the project work due to their own work commitments, and they felt regret at joining the project late.

These accounts of the patient representatives' experiences point to suggestions that future studies would benefit from developing and maintaining a robust strategy for recruiting service users, especially about the timing of recruitment, and managing service users' expectations.

Emerging from this study comes much congruence with features of service user involvement which were already known. Patient representatives knew what health and care services were available to them and what needed to be improved. They set aside their own experiences and engaged in discussion about new ways of working with shared goals which led to the co-production of health care improvements. Findings included the capacity for patients to understand complex issues and to innovate, their ability to lead, the significance of creating the right learning environment and that co-learning is a model that can help deliver the goals of service improvement through service user involvement. Patient representatives experienced emotion in their engagement; they expressed regret when their engagement began too late and when they were unable to work together with their own practice team. Patient representatives were creative tools in the improvement

process and motivators of the teams with some of them taking leadership roles. Preparation and understanding of the environment, providing time, and establishing clear and open communication processes were all important components of the co-learning environment which were important to patient representatives.

The preparation of the environment to include adequate time, the provision of information and on-going support for service users, in a variety of styles and formats would benefit service users in similar studies in the future.

Many aspects of learning about service user involvement in this study have been reported by other researchers. The current state of the knowledge base about service user involvement has expanded over the lifetime of this study and is now beginning to address the gaps such as in the quality of reporting such studies, in the theoretical and methodological frameworks for service user involvement and in research methods. A variety of models for involving service users are suggested and there is an increase in the breadth of service user involvement studies across the healthcare and education sectors. Studies involving service users are now published more frequently reflecting the implementation of statutory duties for health and social care organisations resulting in a wider range of current activity and greater interest from academics and health professionals.

Conclusions from this study show that using a pragmatic approach did succeed in findings answers to the research question and such an approach might be useful for researchers designing future similar studies.

9.1.1   Meeting the study aims

Research studies which involve service users might do so because of the requirements of a legislative process but the aims for user involvement should be clear. Where the purpose of user involvement is not clear, tokenism might be suspected. This study found that the purpose of service user involvement in the wider research project was clear; it was stated in the supporting information for patient representatives and it was documented in the project protocol.

The study aimed to evaluate the extent to which the goals for involving patients in the LIMBIC project were met. It found that patient representatives did engage with practice teams in influencing their decisions about topics for their improvement projects. The extent to which user involvement processes had an impact on the LIMBIC project outcomes was demonstrated by their influence on the improvements made in the practices. This study found that another of the goals of the LIMBIC project – that of recruiting a patient representative to each of the nine practice teams - was not achieved. Although remedial plans were put in place to recruit patient representatives through informal networks and via other practices, this weakness in the recruitment strategy influenced the service user experience in that it led to some feelings of regret for those service users who were recruited later and therefore joined the project after it had started.

As well as producing this account of the patients' experiences, this study aimed to highlight the features of their experiences that might be relevant for future studies involving service users. These are presented as recommendations below, in addition to the model for co-learning to influence change.

9.2   Recommendations from this study

Recommendation 1:
Recruitment of service users should be supported by a robust strategy

Funding bodies and research teams should aim to develop robust strategies for the recruitment of service users. Time and effort should be taken to explain to service users what they can expect from being involved and about the purpose of the study and the purpose of involving service users. Researchers and participants should be clear about the goals for involving service users. Expectations for service users might include; learning about their health condition, offering opinions and advice about project plans, meeting other service users or co-learners, learning about and from others and effecting change in health care delivery. Co-learners might take the lead in sharing information with others about their condition or in other ways which support the project aims. Expectations might not be met for everybody.

Time should be made for introducing the project and for people to get to know each other, for relationships to build and for people to begin to work together. Time should be allocated to prepare the support strategies needed by service users for providing that support. Time to plan the service user involvement strategy for the project should be allocated at the design stage of the study.

Recommendation 2:

The environment should reflect the partnership approach and values

The learning environment should be fully prepared drawing upon existing evidence about what works well. Health care professionals work well together in a learning environment which is separate from their usual work place, for example in a community setting. Supporting information and reimbursement processes should be in place before service users are invited to join a project and monitoring of the environment should occur.

Recommendation 3:

Ground rules and support systems are needed for communication

Good communication channels need to be maintained through continuous feedback and open discussion. These can be provided through a variety of mechanisms including traditional methods and newer social media approaches. Mutual respect should underpin these processes. Language should be agreed, possibly through setting ground rules, and medical terms should be kept at a level that everyone can understand.

Recommendation 4:

The model for co-learning should be adapted as required and implemented

Service users might benefit from being involved in future studies which adopt the principles of the model for co-learning arising from this research. Future researchers and health care professionals who engage with service users as co-learners could benefit from using the model for co-learning to design and implement their strategy for service user involvement.

Recommendation 5:

The methodology should draw upon existing evidence about what works

There is continued debate in the literature about the most appropriate ways of undertaking research involving service users. Taking a philosophical perspective based on pragmatism, the methodology used for this study was a qualitative inquiry also using a pragmatic approach towards the research question. Future researchers might wish to consider using pragmatism for studies such as this which involve service users and where timescales and data sources are not all under the control of the researcher and where several data sources require analysis and further integration. The limitations of a pragmatic approach which are discussed below should also be considered.

9.3 Limitations of this study

Limitations relate to weaknesses in the design or undertaking of the study which could influence the outcome and therefore need to be addressed as part of the reporting of the study. Many of the limitations of this study have been acknowledged throughout this thesis and are summarised here.

9.3.1 A limited perspective

One of the limitations of recommending this model for use by health professionals, educators and researchers in developing their work with service users is that the model has been developed using data that explored the service user experience, specifically from the service user perspective and not that of the healthcare professional. There could have been different recommendations and different components of the model if the study had been designed to include exploration of the experiences of health professionals as co-learners with service users. This could be an area for further research.

The focus of this study is in co-learning and the model uses the underlying principles which support co-learning such as being non-hierarchical and valuing

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people equally but because I am presenting the view of one party in the co-learning model, that of the service user, this means that any recommendations will have limitations. However, as the service user perspective is lacking in previous studies the co-learning model has value in its one perspective. The implication of this limitation is that it contradicts the notion of partnership working which is an outcome of the co-learning relationship.

Further research should explore the idea of another co-learning model drawing upon the perspectives of all the participants.

9.3.2   Searching the literature

Many of the challenges in identifying literature about service user involvement which were faced at the outset of this study still remain. There is now more guidance for researchers about reporting studies about service user involvement which can be used to improve the task of searching the literature for researchers in the future. If a study like this one were to be undertaken again, the search strategy would be based upon a much improved evidence base consisting of several systematic reviews of service user involvement and patient and public involvement which have been reported in the more recently published literature. The academic and practice development journals publish service user involvement studies more frequently and many have published special issues about service user involvement. This has greatly improved the breadth of evidence about service user involvement, but there is still much debate about the difficulties of searching for literature. In response to this, researchers have developed guidelines for authors reporting research which, if used, will improve the ability of others to find studies in their searches.

9.3.3   Methodologies and methods for service user involvement research

Searching for the best approach for undertaking this study failed to find a good fit with the research question. Researchers and health professionals involving service users in their work have arrived at agreement that there is not one best approach or theory for undertaking service user involvement research. The early developments of research with service users were in disability research and in research with

mental health service users. Approaches used in these areas were emancipatory and user-led research where the service users led the research. A user-led approach might have been possible in this study if the timing of the study had been different. If this current study had been designed at the same time as the LIMBIC project therefore allowing the service user evaluation component and the exploration of the service user experience to occur in parallel, the study might have been able to capture different, more current data.

The pragmatic approach for this study was appropriate in that it permitted the exploration of a wide range of different types of data and the use of triangulation methods in the analysis provided for a robust analysis. In contrast, the large amount of data that were available made the data collection and analysis processes complex and it became a challenge to report these in a clear and comprehensive way. This was addressed by developing a data analysis strategy at the start of the data gathering process. The way in which the three stages of data were integrated at the end of the analysis process was complicated and whilst a systematic approach was taken, it was difficult to report exactly on the way in which parts of documents were analysed when content analysis overlapped critical analysis and thematic analysis. There might have been a way of analysing each set of data individually and building codes and categories throughout, but this too would have been a lengthy approach with potential for losing some of the richness of data that did emerge by analysing the semi-structured interview transcripts early in the analysis process.

An experimental, quantitative approach was not considered suitable for this research due to its goal of seeking the perspective of service users which traditionally uses a qualitative approach as this can gain in depth analysis understanding of human behaviour. Action research would have suited this study as the focus is on working with communities to bring about change. Participatory action research would be particularly relevant due to the nature of the role of service users in this study as co-learners. The idea of action research is where a community of people work together with common interests or goals to achieve change. The community is well positioned to find solutions to particular problems, and as in this research, in identification of problems that were of particular interest to patients, with

back pain. The research might also have been possible through user-led or user-controlled (emancipatory) research. The focus of this type of research is about service users holding the power and being in control and would have been particularly suited to this research, but only if the timing of the study had been different. When this study was being designed, the LIMBIC project was already underway working with service users. It would have impacted on the LIMBIC project if work with the service users was attempted whilst they were still in role as service users and co-learners in the LIMBIC project.

The use of pragmatism as a methodological framework for this study drew away from the idea of a typical qualitative paradigm. As such it allowed for a variety of methods of data collection and analysis and so there was no restriction to the use of one approach. My own personal values guided the decision-making and to some extent this meant that I anticipated the sort of findings which might emerge. I did not have any discomfort with addressing my research question in this way although some researchers have argued that the values which drive the research may be those of the participants, policy makers or people who are seen as having positions of power. I tried to take a neutral stance in relation to the decision-making but also I recognise that as a researcher and therefore a research tool in this qualitative study I would undoubtedly influence the outcomes. The use of reflexivity through the research process has attempted to balance this argument.

In relation to the limitations around the methods used, interviews were held in different settings and they were also undertaken in a different setting to that of the LIMBIC study, which might have produced different data. Interviews were also undertaken some time after the participants' interaction in the LIMBIC project (between three and eleven months) and could therefore be subject to problems of recall. As researcher undertaking the interview I was known to them and this could have influenced how they answered the interview prompts and what they chose to talk about in their interviews. Not all participants were equally articulate and perceived things in different ways but this was not an issue for this research because it was what the patient representative talked about that was important for this research. The use of semi-structured interviews permitted a large volume of

data to be collected but this led to the challenge of data analysis being a time consuming exercise.

With regard to the analysis, the documentary analysis took a different approach depending upon the type of document and it required the researcher to search out information that was relevant to the research question. Working with audio-visual material was a new way of working and advice needed to be sought from experts in the field. This meant that there was a novice approach to the analysis of these data which might have influenced the detail of the findings. Manual coding of the data and manual thematic analysis was the analysis method chosen. Qualitative data analysis computer software could have been used in this study but as researcher I felt comfortable working using manual processes. I have gained the skills of using qualitative data analysis software but if I were to undertake the analysis process again I would still choose to take a manual approach to data analysis.

Inter-rater reliability was not undertaken because there was only one researcher and therefore this was not appropriate. It might be argued that the validity of the coding could have been improved through a reliability check or through multiple coding but this was not considered appropriate as the researcher was the research instrument for this process and a team based approach had not been used for this research.

9.3.4   If this study were to be repeated

If I had the opportunity to undertake this study again, there are several things I would do differently. I would involve the service users in deciding upon the research question and the research approach that would best suit the study question. If this was not possible or if the approach had already been decided the service users would be involved in setting objectives for service user involvement in the study. I would also involve service users in deciding which data to collect for use in this study, how it should be collected and in the analysis process to help with interpretation of the data in relation to language to avoid misinterpretation. They might have collected data themselves, for example through peer interviewing and they might have considered it relevant to interview members of the research team,

the practice teams or the research funders. They might have made different decisions about what primary data and secondary data might have been suitable to collect and about how it should be analysed. If done again, this research would involve service users at all stages of the research process including the research approach, the research question and the methods and analysis. If the patient representatives led the study themselves the findings might have been different if different questions had been asked and different interpretations had been made about the content of the interviews. However, the co-learning model might not have emerged if the study had been undertaken in a different way with different interviewers asking different questions.

If done again I would design the study in such a way that it was not dependent upon the LIMBIC project structures and processes. I would design the service user involvement exploration to begin at the same time as the larger project and with its own discrete approach without depending upon or interfering with any of the LIMBIC project processes. This could be undertaken by building its design integral to the LIMBIC project.

Drawing upon data from an existing, concurrent study has limited the extent to which I was able to shape the data collection processes and the type of data that were used. Being dependent upon its parent study, the LIMBIC project, reporting the findings of these two inseparable studies has inevitably led to the use of some repetition.

When designing this study I did consider undertaking a second round of interviews with patient representatives if this became relevant once the data had first been analysed. This did not happen mainly because it became irrelevant due to the fact that the analysis was not undertaken until two years after the data collection. Had I wanted to return to the participants to request a second interview, it is likely that much would have been forgotten in the intervening time period, so making the exercise less relevant. Had I been able to return to the participants a year after their first interview with specific questions about things which were emerging from the data, this might have revealed some different findings. I might have been able to seek confirmation about emerging findings for example.

If I undertook a similar study again I would plan the research design to ensure the data collection processes were not unduly influenced by other project timelines. In this current study, there was plenty of time to plan the research and this was supported through doctoral supervision, but the concurrent LIMBIC project was always a few steps ahead and this created a sense of needing to maintain a pace. This gives another reason for undertaking the service user component in parallel with the main study. Action research might have lent itself to such an approach.

A major limitation was around the influence upon the research process due to my dual role in the LIMBIC project as researcher and project manager. As such, I was not external to the LIMBIC research intervention and this could be seen to have caused bias and influence the rigour of this research. However, as a qualitative researcher, the research process involves being immersed in the setting and this could be seen as a strength in the interpretation and definition of the study outcomes.

Undertaking a doctoral study in the wider context of a larger funded study is likely to have influenced the way I designed and undertook the study. As researcher for the LIMBIC project, the funding source for my employment was from the same source as the funding for the LIMBIC project. I therefore had a vested interest in ensuring both of these projects were delivered to a high standard and on time. I see this as a positive influence on both studies and recognise that the study progress might have been different had I not had the dual roles. The research team leading the LIMBIC project was a constant support to me in both these roles and this therefore had a contribution to the way in which this current study was undertaken.

I have maintained a reflexive approach towards reporting this research throughout this thesis to redress the potential influences I brought to the process. My role as researcher working on the LIMBIC project differed from the usual studentship status of many doctoral researchers in relation to their own studies and I recognise this as a limiting factor in this research. In meetings with my doctoral supervisory team I was constantly reminded to maintain an awareness of keeping the two roles

separate whilst maintaining a critical stance towards the data from this current study.

In deciding upon the sample, there was no intention to look for typicality across the individuals. There was no attempt to gain a sample that was representative of a particular population; it was the legitimacy of their contribution which was important. The LIMBIC patient representatives did not claim to represent all back pain sufferers, the sample was not meant to be representative in any way. The size of the sample for the study did not allow for generalisations to be made to other studies involving service users but this was never an intention. The richness of the data did, however, allow for gaining an insight into the service user experience and this has illuminated a perspective, that of the service user, that was previously unknown. The sampling strategies used in this study supported the purpose of the study and were relevant to the research question. A large sample size of patient representatives was not necessary or appropriate because it was the richness of data that gave insight through thick description to the qualitative inquiry alongside my own analytical capability.

9.4 Application in the context of current UK healthcare

Opportunities for people to learn about the results of health service research are now common-place. Research findings frequently appear in the public domain and discussions about their efficacy and ethics continuously attract media attention. There is less secrecy and academic elitism surrounding the reporting of research findings today compared to a couple of decades ago. There is more known about research processes, for example it is known that much research goes unreported, and this might be because the findings were unexpected or the expectations for the study question remained unanswered. It is known that GPs are involved in planning and commissioning health services. Whilst it is not always clear why, it is known that some patients are denied treatments which others freely receive in other parts of the same country. Because the general public knows more and understands more, and because reliable information is now so much easier to access, members of the public are even better placed than before to take up their service user positions as leaders.

The research described in this study is a small scale project undertaken in a medium sized university exploring the experiences of a small number of people from a nation which uses the same single publicly-funded healthcare organisation. During the undertaking of this study, from 2008 to 2013, that National Health Service experienced many changes. These changes were in the structure, organisation and delivery of health services as well as its monitoring and regulation. Many of the new imperatives have promoted an increasing focus on the role of the patient as participant and adviser in the decision-making processes about healthcare and its delivery. Lay membership is mandatory for Clinical Commissioning Group Boards, Foundation Trust Boards and many other corporate bodies of large public service organisations. Lay membership goes some way towards transparency of committee functions and public engagement but working on the front line, alongside healthcare professionals is often where lay people can make a difference. This study offers co-learning as a potential new direction for changing health services to better reflect the needs of patients.

In addition to the ever-changing structure of the NHS which were continuous throughout the lifetime of this study, a report from an inquiry into the failures at Mid Staffordshire Hospitals Foundation Trust (Francis 2013) led to further dramatic changes. Large scale inquiries are rare and yet the legislation, regulation and monitoring systems which have followed previous inquiries, seem to have failed in preventing recurrence. The focus on the role of service user involvement seemed not to have made a difference in the quality of care for patients at this Trust. At the time of writing up this study, the full impact of the mid-Staffordshire story is currently unknown. Changes in legislation are underway. Improvements will be mandatory and monitored. They will be implemented and their impact is not yet known. The Francis Inquiry Report included stories told by patients and their families and carers. The stories will have impact on those who hear them, whether these listeners are health care professionals worried about the way things are happening in their Trust, or whether they are people who choose to engage in health research. In this study, the patient representatives who engaged with health care teams asked the research team if they could tell their stories. Their stories were heard. Relationships changed. Formalities were shelved. Cohesion and co-learning, respect and trust formed the

goals and values of a shared endeavour, and team effort resulted in unexpected change.

For many years researchers and health professionals have engaged with service users in routine practice such as planning, delivery and evaluation of health services, research and education. Service user voices are now being heard. It seems this approach is not yet widespread enough, and, more importantly, not enough is known about the service user involvement experience. It is important that researchers take service users' experiences into account and ask whether there are things they could be doing better.

This study has illuminated aspects of the service user experience that were not previously known and it has suggested a model for use in future co-learning initiatives with service users to bring about change. It has contributed to the wider knowledge of service user involvement by identifying features of their experience that worked well for them and features that could be improved. This has led to recommendations for future studies and it has opened a debate for the future about managing expectations for service users and about their potential for leadership and influencing change.

There is still a long way to go in the challenge to demonstrate the impact of service user involvement, but we can now ensure that their involvement journey is neither poorly informed, ill-timed or ineffectively communicated. The leadership potential for service users in influencing healthcare is gaining momentum. The roles of health care professionals and patients as leaders are being redefined. As health care professionals are starting to think differently about the way they practise and the way they communicate, patients too are shifting in their thinking about their partnership role in the transformation that is happening in healthcare. This study identifies some of the ways in which they can be supported in their important role.

10. References

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Appendices

Appendix 1

Author's Declaration – supporting information

Author's Declaration – supporting information

A1. Author's role in the LIMBIC project

Louise Worswick was Project Manager and Researcher for the 3 year externally funded LIMBIC project. In the Project Manger role she had contact with the service users/ patient representatives in the LIMBIC project who later became participants in this study.

This contact with service users in the LIMBIC project involved supporting them in their service user involvement role, providing information about the educational events, maintaining email contact, liaising with them about the LIMBIC project through telephone calls, emails and the project wiki and supporting their peer group meetings.

In her researcher role she had contact with the service users/patient representatives through focus groups with practice teams and their patient representatives, which included administration of the consent process, undertaking the focus groups and analysing the data for the wider LIMBIC evaluation study.

Further detail about the LIMBIC project is provided throughout the thesis where appropriate and it is made clear when data from the LIMBIC project are used in this current study.

A2. Presentations of this research 2010-2013

Journal Articles

Worswick, L., Little, C., Ryan, K. and Carr, E. (2013) Service user perspectives of involvement in an education evaluation study of back pain and quality improvement learning. Submitted to *Public Management Review Special Issue* [In review].

Worswick, L., Little, C., Ryan, K. and Carr, E. (2013) Involving service users in quality improvement learning in primary care – a model for co-learning. Due to be submitted to *Nurse Education Today Special Issue* by 15 November 2013.

Conference presentations

2nd Global Congress for Qualitative Health Research,
Università Cattolica del Sacro Cuore, Milan, Italy, 28-30 June 2012
Worswick, L., Little, C., Ryan, K., Carr, E.
Presentation: Patient perspectives of co-learning with primary health care teams

Bournemouth University, School of Health and Social Care
PhD Seminar, 26 September 2012
Louise Worswick
Presentation: An exploration of the experience of patients who participate in research as co-learners with primary health care teams

Sigma Theta Tau, Phi Mu Chapter (England), Putting People at the heart of Nursing Care: leading the way, Bournemouth University, 21 June 2013
Worswick, L., Little, C., Ryan, K., Carr, E.
Presentation: Involving service users in co-learning with primary care teams

NET2013, 24th International Networking for Healthcare Education Conference, Fitzwilliam College, University of Cambridge, 3-5 September 2013
Worswick, L., Little, C., Ryan, K., Carr, E.
Presentation: Involving service users in quality improvement learning in primary care.

Conference posters

Centre for the Advancement of Interprofessional Education (CAIPE) Annual General Meeting, London, 24 June 2010.
Louise Worswick
Poster: An exploration of the experience of patients who participate in research as co-learners with primary health care teams
Student poster competition winner (postgraduate researcher category)

INVOLVE 7th National Conference Public involvement in research: innovation and impact, Nottingham, East Midlands Conference Centre, 16-17 November 2010.
Louise Worswick
Poster: "It didn't begin as a research project about involvement…"

Bournemouth University Graduate School Third Annual Postgraduate Research Student Conference, 12 January 2011.
Louise Worswick
Poster: An exploration of the experience of patients who participate in research as co-learners with primary health care teams.

INVOLVE 2012 Conference – Putting people first in research
Nottingham, 13-14 November 2012
Louise Worswick, Chris Little, Kath Ryan, Eloise Carr
Poster: Involving service users as co-learners in research about quality improvement, interprofessional education and back pain: the service user perspective

Appendix 2

Levels of evaluation in the LIMBIC project evaluation

Levels of evaluation in the LIMBIC project   **Appendix 2**

☻ = patient representative

Patient representatives join the project ☻ ☻ ☻	High level evaluation	**Quantitative approach**
	Baseline data collection Nine practices from two Primary Care Trusts	Before and after outcome measures through questionnaires with patients
		Qualitative approach
Patient representatives participate in the workshops ☻ ☻ ☻ ☻ ☻ ☻ ☻	Practice level evaluation	Focus group interviews with workshop participants; GP, Practice nurse, receptionist, patient representative ☻, Fast Feedback evaluation
	Eight workshops with nine practice teams over 9 months ☻ Practice improvement projects undertaken ☻ Practice level evaluation after workshops ☻	
Patient representatives describe their experiences ☻ ☻ ☻ ☻ ☻ ☻ ☻	High level evaluation	**Quantitative approach**
	Repeat data collection Nine practices from two Primary Care Trusts	Before and after outcome measures through questionnaires with patients

Appendix 3

Search Strategy

Search strategy

A3.1   Initial ideas for the Research Question

The experience of patients or service users who participate in research as co-learners with primary health care teams.

A3.2   Key words

Key words	Boolean operators
Service user	
Patient representative*	OR
Co-researcher*	OR
Service User	OR
User	OR
Lay expert	OR
Lay perspective	OR
Lay representative	OR
Patient	OR
Participant	OR
Consumer	OR
Co-learn*	
Involvement	AND
User involvement	OR
Service user involvement	OR
Patient involvement	OR
Participat*	OR
Public involvement	OR
User-led	OR
Consultation	
Research area	AND
Research	OR
Health*	OR
Inter-professional education	OR
Interprofessional	OR
Learning	OR
Education	OR
Primary care	

Table A3.1 Search terms

A3.3.   Parameters

Publication date	January 1990 to May 2008
Language	English language
Search terms in:	Title only
Types of publication	Peer reviewed Primary research English language Systematic review

A3.4 Sources

Databases	web-based resources
Academic Search Complete British Nursing Index CINAHL Cochrane Library ISI Web of Knowledge Ovid Medline NHS Evidence SIGLE PsychARTICLES PsychBOOKS PsychINFO Scirus Scopus SocINDEX UK PubMed Central	INVOLVE bibliography (Volume One 2007) COMENSUS website: the approach to involving service users, carers and the wider community across the University of Central Lancashire Patient and Public Involvement network CHAIN network for researchers in primary care
e-journals	e-bulletins
British Medical Journal Health Expectations Nurse Education Today Journal of Interprofessional Care Health and Social Care in the Community Quality and Safety in Healthcare Quality in Health Care	INVOLVE bulletin The King's Fund Department of Health Chief Nursing Officer Care Quality Commission Royal College of Nursing Health Foundation Research Scans Patients Association NHS networks

A3.5 Exclusion criteria

Involvement in clinical trials
Involvement as volunteers
Patient and Public Involvement in delivering health services
Patient satisfaction studies (satisfaction with services)
Patient and Public Involvement in service provision
Patient and Public Involvement in treatment decisions
Access to services

A3.6 Storage

References were saved to a file in Endnote web
Hard copies of papers were filed in researcher file storage

Appendix 4

Ethics approval

1. Approval letter from Ethics Committee 20 November 2008 (AM03)
    (committee members names not included)

2. Notice of substantial amendment 2 (AMO2)

3. Notice of substantial amendment 3 (AMO3)

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.
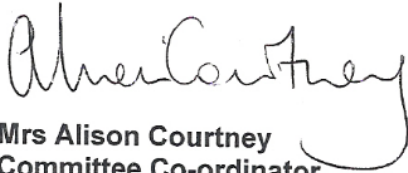
Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

07/H0205/36:	Please quote this number on all correspondence

Yours sincerely

(signature)

Mrs Alison Courtney
Committee Co-ordinator
Somerset Research Ethics Committee

E-mail: alison.courtney@tst.nhs.uk

Enclosures   List of names and professions of members who were present at the meeting and those who submitted written comments

SB/ac/07/H0205/36

09 December 2008

Dr Eloise C J Carr
School of Health & Social Care
Royal London House, Bournemouth University
Christchurch Road, Bournemouth
BH1 3LT

Dear Dr Carr

Study title:	Improving the management of back pain in Primary Care: an interprofessional approach linking practice based learning with the principles and methods of healthcare improvement.
REC reference:	07/H0205/36
Amendment number:	AM03
Amendment date:	20 November 2008

The above amendment was reviewed at the meeting of the Sub-Committee of the REC held on 03 December 2008.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Participant Information Sheet	2.0 Patient representative interview	19 November 2008
Participant Consent Form	2.0 Interview - back pain	19 November 2008
Notice of Substantial Amendment (non-CTIMPs)		20 November 2008
Letter of invitation to participant	2.0	19 November 2008
Interview Schedules/Topic Guides	2.0 Patient interview protocol	21 November 2008

This Research Ethics Committee is an advisory committee to South West Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

NOTICE OF SUBSTANTIAL AMENDMENT

For use in the case of all research other than clinical trials of investigational medicinal products (CTIMPs). For substantial amendments to CTIMPs, please use the EU-approved notice of amendment form (Annex 2 to ENTR/CT1) at http://eudract.emea.eu.int/document.html#guidance.

To be completed in typescript by the Chief Investigator in language comprehensible to a lay person and submitted to the Research Ethics Committee that gave a favourable opinion of the research ("the main REC"). In the case of multi-site studies, there is no need to send copies to other RECs unless specifically required by the main REC.

Further guidance is available at http://www.nres.npsa.nhs.uk/applicants/review/after/amendments.htm.

Details of Chief Investigator:

Name:	Dr Eloise C J Carr
Address:	School Of Health and Social Care
	Royal London House, Bournemouth University
	Christchurch Road
	Bournemouth BH1 3LT
Telephone:	01202 962163
Email:	ecarr@bournemouth.ac.uk
Fax:	01202 962194

Full title of study:	Improving the management of back pain in Primary Care: an interprofessional approach linking practice based learning with the principles and methods of healthcare improvement. *also known as* Learning to Improve the Management of Back pain In the Community (LIMBIC)
Name of main REC:	Somerset Research Ethics Committee
REC reference number:	07/H0205/36

Date study commenced:	13 August 2007
Protocol reference *(if applicable),* current version and date:	Version 7, 28 January 2008
Amendment number and date:	Amendment No 2, 7 October 2008

Type of amendment (indicate all that apply in bold)

(a) Amendment to information previously given on the NRES Application Form

       Yes   ***No***

       If yes, please refer to relevant sections of the REC application in the "summary of changes" below.

(b) Amendment to the protocol

       Yes   No

       If yes, please submit <u>either</u> the revised protocol with a new version number and date, highlighting changes in bold, <u>or</u> a document listing the changes and giving both the previous and revised text.

(c) Amendment to the information sheet(s) and consent form(s) for participants, or to any other supporting documentation for the study

       Yes   ***No***

       If yes, please submit all revised documents with new version numbers and dates, highlighting new text in bold.

Is this a modified version of an amendment previously notified to the REC and given an unfavourable opinion?

       Yes   *No*

Summary of changes

Briefly summarise the main changes proposed in this amendment using language comprehensible to a lay person. Explain the purpose of the changes and their significance for the study. In the case of a modified amendment, highlight the modifications that have been made.

If the amendment significantly alters the research design or methodology, or could otherwise affect the scientific value of the study, supporting scientific information should be given (or enclosed separately). Indicate whether or not additional scientific critique has been obtained.

Part of this project, already given a favourable ethical review, involves focus group interviews with the 9 participating Practice teams. These occur on two occasions, one before the commencement of a series of eight Workshops (in the early part of 2008) and one after the series of Workshops has taken place (January/February 2009). The Practice teams include a patient representative for each Practice. The consent process is undertaken with all participants for this activity.

The purpose of the focus group is to gather information to contribute towards the evaluation of the series of eight educational Workshops by exploring expectations of learning and working together. Participants have been informed that anonymised, non-attributable results will be reported to the funding body (the Health Foundation), Bournemouth University, participating PCTs and more widely at conferences and in medical and health journals.

Since the start of the project the project manager for LIMBIC has commenced a postgraduate research degree (PhD) alongside the LIMBIC project and is intending to explore the experience of user involvement in research. Data generated from the LIMBIC project patient representatives would be immensely helpful in meaningfully informing the design and development of this research.

This would involve using the data collected for the LIMBIC project for 'another purpose' and this is the reason for this substantial amendment request.

Permission is sought to use the data gathered from the patient representatives of LIMBIC to help inform the study design for a research degree. It is intended that once the study design for this research degree has been developed sufficiently, a further full ethics application would be made to the National Research Ethics Service, if appropriate.

If it was considered acceptable to the Research Ethics Committee the researcher could approach the patient representatives and ask for consent to use this data to inform the design and development of a further study.

Any other relevant information

Applicants may indicate any specific ethical issues relating to the amendment, on which the opinion of the REC is sought.

| | | |

List of enclosed documents

Document	Version	Date

Declaration

- I confirm that the information in this form is accurate to the best of my knowledge and I take full responsibility for it.

- I consider that it would be reasonable for the proposed amendment to be implemented.

Signature of Chief Investigator:

Print name: …Dr E.C.J. Carr….…………

Date of submission: …10 October 2008………….

NHS
National Patient Safety Agency

National Research Ethics Service

NOTICE OF SUBSTANTIAL AMENDMENT

For use in the case of all research other than clinical trials of investigational medicinal products (CTIMPs). For substantial amendments to CTIMPs, please use the EU-approved notice of amendment form (Annex 2 to ENTR/CT1) at http://eudract.emea.eu.int/document.html#guidance.

To be completed in typescript by the Chief Investigator in language comprehensible to a lay person and submitted to the Research Ethics Committee that gave a favourable opinion of the research ("the main REC"). In the case of multi-site studies, there is no need to send copies to other RECs unless specifically required by the main REC.

Further guidance is available at http://www.nres.npsa.nhs.uk/applicants/review/after/amendments.htm.

<table>
<tr><td>Details of Chief Investigator:
Name:
Address:

Telephone:
Email:
Fax:</td><td>
Dr Eloise C J Carr
School of Health and Social Care
Royal London House, Bournemouth University
Christchurch Road
Bournemouth BH1 3LT
01202 962163
ecarr@bournemouth.ac.uk
01202 962194</td></tr>
</table>

Full title of study:	Improving the management of back pain in Primary Care: an interprofessional approach linking practice based learning with the principles and methods of healthcare improvement. *also known as* Learning to Improve the Management of Back pain In the Community (LIMBIC)
Name of main REC:	Somerset Research Ethics Committee
REC reference number:	07/H0205/36
Date study commenced:	13 August 2007
Protocol reference *(if applicable),* **current version and date:**	Version 7, 28 January 2008
Amendment number and date:	Amendment No 3, 20 November 2008

Type of amendment (indicate all that apply in bold)

(a) Amendment to information previously given on the NRES Application Form

No

(b) Amendment to the protocol

No

(c) Amendment to the information sheet(s) and consent form(s) for participants, or to any other supporting documentation for the study

Yes, *additional new documentation is enclosed.*

If yes, please submit all revised documents with new version numbers and dates, highlighting new text in bold.

Is this a modified version of an amendment previously notified to the REC and given an unfavourable opinion?

No

Summary of changes

Briefly summarise the main changes proposed in this amendment using language comprehensible to a lay person. Explain the purpose of the changes and their significance for the study. In the case of a modified amendment, highlight the modifications that have been made.

If the amendment significantly alters the research design or methodology, or could otherwise affect the scientific value of the study, supporting scientific information should be given (or enclosed separately). Indicate whether or not additional scientific critique has been obtained.

This project has involved a series of eight Workshops with nine practice teams across NHS Bournemouth & Poole, and NHS Wiltshire. Focus group interviews with the participating Practice teams were carried out; one before the commencement of the Workshops, in the early part of 2008, and there is another one due to take place after the series of Workshops has taken place (early 2009). The Practice teams include a patient representative for each Practice and the patient representatives have been involved in the focus group interviews. The consent process has been undertaken with all participants for the focus groups.

The project manager for LIMBIC (Louise Worswick) is undertaking a postgraduate research degree (PhD) alongside the LIMBIC project and intends to explore the experience of user involvement in research. Permission was sought and approval given by your committee to use the existing data gathered from the patient representatives of LIMBIC to help inform the study design for this research degree (AM02 10 October 2008).

The study design for this research degree has now been developed and it is intended that the researcher carries out a one-to-one interview with each patient representative on the LIMBIC project in order to gain information to explore the experience of the patient

representative as co-researcher – not previously reported in the literature for a project of this nature. Depending upon the findings of these interviews, the researcher may wish to undertake one further follow up interview with each patient representative. A proposed interview schedule is included with this amendment form.

A risk assessment will be undertaken prior to any interview taking place. It is worth noting that during the course of the LIMBIC project there was discussion about what support was available for patients who may become distressed during the course of the workshops. The LIMBIC Steering Group considered a variety of support strategies and decided to discuss with the patient representatives themselves what they would like to have access to in the event of unexpected distress. The outcome of these discussions was that patient representatives felt that they did not need any specific support, they felt comfortable in discussing any issues with members of the LIMBIC project team either from their own practice or from the LIMBIC Steering Group. Subsequently, Steering Group members made themselves available for support after each workshop and all patient representatives have access to the BackCare helpline.

The researcher intends to use the data gathered through the LIMBIC project for the patient representatives to add to the data gathered through the interviews with patients in order to achieve the project aims. These data include patient stories, notes from meetings, patient logs, diaries and ad hoc meetings.

The purpose of this application to your Ethics Committee is to seek approval for the patient representatives to be invited to give either one or two (if follow up is deemed of value) interviews with the researcher. This would be in addition to attending the focus group interview with the Practice for which the patient representatives have already given their consent.

To assist with clarity a study code has been allocated to this new part of the study LIMCOR/LW/08.

Any other relevant information

Applicants may indicate any specific ethical issues relating to the amendment, on which the opinion of the REC is sought.

List of enclosed documents

Document	Version	Date
Participant information sheet – patient representative interview	2	19 November 2008
Consent Form – Consent to interview – patient representative	2	19 November 2008
Letter to patient representative	2	19 November 2008
Proposed interview protocol	2	21 November 2008

Declaration

- I confirm that the information in this form is accurate to the best of my knowledge and I take full responsibility for it.

- I consider that it would be reasonable for the proposed amendment to be implemented.

Signature of Chief Investigator:

Print name: …Dr E.C.J. Carr…………….

Date of submission: …20 November 2008………….

Appendix 5

1. Letter of invitation to participate

2. Participant Information Sheet

3. Patient representative interview consent form

CONSENT FORM

Learning to improve the management of back pain in the community

Consent to interview – patient representative

Please initial the boxes below

1. I confirm that I have read and understand the information sheet dated
    19 November 2008 (Version 2) for the above study. ☐

2. I have had the opportunity to consider the information and ask questions. ☐

3. I have had my questions answered satisfactorily. ☐

4. I understand that my participation is voluntary and that I am free
    to withdraw at any time, without giving any reason, without my
    medical care or legal rights being affected. ☐

5. I understand that I will participate in an interview with the researcher
    and that this will be tape recorded and documented for research purposes. ☐

6. I understand that there may be a second interview a year later. ☐

7. I agree to take part in the above study. ☐

8. I give consent for my GP to be informed that I am participating in the study ☐

9. I wish to be informed of the study results ☐

_____   _____   _____
Name of Patient representative   Date   Signature

_____   _____   _____
Researcher   Date   Signature

When completed, one copy for patient; one copy for researcher site file.

Learning to Improve the Management of Back pain
In primary Care (LIMBIC)

Part 1.

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. Talk to others about the study if you wish.

Part 1 tells you the purpose of this study and what will happen to you if you take part.

Part 2 gives you more detailed information about the conduct of the study.

Ask the researcher 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.

What is the purpose of the study?
Despite the existence of evidence about the management of back pain in primary care, GPs still have difficulties in successfully managing back pain for very many of their patients. The LIMBIC study has been working with GPs and their teams in trying to develop ways in which they can improve the management of their patients with back pain. These practice teams have included a patient representative who has an equal role as co-researcher in the programme of workshops and in the improvement project work undertaken by practices. This new study is going to explore the experience of the patient as co-researcher to gain an understanding of their experience in this role.

Why have I been chosen?
You have already begun to participate in the LIMBIC Study as a patient representative to support the practice teams in their improvement work, and to influence the LIMBIC workshops through your comments and actions. This new study is an exploration of the experience of the patient representative experience as co-researcher and you have been chosen to be invited to give an interview because you are one of those patient representatives.

Do I have to take part?
Not at all. It is entirely up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and the researcher will contact you to answer any questions you may have, and book a time for the interview. If you agree to participate in the interview, you will be asked to sign a consent form (with a copy for you to keep).

You are free to withdraw from the study 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 the care you receive in your practice in any way.

What will happen to me if I take part?
You will be invited to participate in an interview with the researcher to discuss together your experience of the workshops and participating in the project generally. The interview will take approximately one hour and will take a semi-structured approach with questions to prompt a general discussion. It will aim to explore your experience of being involved in the project as a patient representative and co-researcher. The interview will take place at the end of the series of workshops in early in 2009. Depending upon the findings of these interviews I may want to ask you to have a further interview one year later (early 2010).

Expenses and payments:
There is no payment for your participation in this part of the research project. The interview will be held at a location that suits you and you will be reimbursed for any travelling costs incurred.

What do I have to do?
By agreeing to take part in the study we expect that you will be able to attend the interview(s) which will be held at a location to suit you and at a time that is convenient. The interview(s) will be recorded.

What are the other possible disadvantages and risks of taking part?
We do not foresee any disadvantages or risks with taking part in this study.

What are the possible benefits of taking part?
Participation in the LIMBIC study may have provided you with a learning opportunity. You are able to express your views about this experience and will have the opportunity to share the perspective you bring as a user of the services. The project may help us to understand more about the experience of patients who are involved in research as co-researchers.

What happens when the research study stops?
Your involvement in the study will stop when the second round of interviews have been completed (January/February 2010), or after the first interview if only one takes place..

What if there is a problem?
Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.'

If there should be a problem identified within the interview that may indicate issues around poor professional practice, this will be taken by the researcher for discussion with the Principal Investigator.

Will my taking part in the study be kept confidential?
Yes. All the information about your participation in this study will be kept confidential. The details are included in Part 2.' The information you provide in the interview will be confidential to you and the researcher.

Contact Details:
Louise Worswick, School of Health and Social Care, Bournemouth University, 2nd Floor, Royal London House, Bournemouth, Dorset BH1 3LT   Tel: 01202 962050

Part 2

What will happen if I don't want to carry on with the study?
You are under no obligation to continue participating in the study should you change your mind. You are 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 care or treatment in the practice.

What if there is a problem?
If for any reason you are unhappy about the way you have been treated in this study you may wish to contact any of the following:

- Dr Eloise Carr – 01202 962163, study investigator at Bournemouth University.

- NHS PALS (Patient Advice and Liaison Service) is able to provide you with confidential advice and support about your local health service - 01202 318954

- Your GP or someone at your doctor's practice.

- If you wish to make an informal complaint you may do this through the Complaints Team at your Primary Care Trust.

- If you are not happy with your response and wish for an independent review, you can contact the Healthcare Commission, FREEPOST NAT 18958, Complaints Investigation Team, Manchester, M1 9XZ.
  Telephone: 0845 601 3012. Email:complaints@healthcarecommission.org.uk
  Website: www.healthcarecommission.org.uk

- If you remain unhappy after independent review then you can complain to the Health Service Ombudsman at Millbank Tower, Millbank, London, SW1P 4QP. Telephone: 0845 015 4033.
  Email: phso.enquiries@ombudsman.org.uk
  Website: www.ombudsman.org.uk

Will my taking part in this study be kept confidential?
All information which is collected during the study which has been contributed by you will not be attributable. Any documentation relating to the interview will be kept in a password-protected computer file which is accessible only by the researcher. After the study, all the data will be stored for eight years and then destroyed.

Occasionally, Bournemouth University may need to review their files and the conduct of the study for the purposes of monitoring the quality of the research they undertake. If this were to occur relating to records of your interview, they would of course keep all information confidential.

The procedures we have used for handling, processing, storing and destroying your data are compliant with the Data Protection Act 1998.

What will happen to the results of the research study?
When the study is finished we may wish to publish general findings in journals or present the findings at conferences. You will not be identifiable, even if quotes are used. We are more than happy to send you a summary of the findings when the

study is complete (We will ask you if you would like this when at the time of conducting the interview).

Who is organising and funding the research?
The research is being undertaken by Louise Worswick, a researcher and PhD student at Bournemouth University who is also managing the LIMBIC project. The LIMBIC project is headed by Dr Eloise Carr and Dr Charles Campion-Smith (School of Health & Social Care, Bournemouth University). This piece of work (the patient interviews), as a project to support a postgraduate research doctorate (PhD) does not have its own source of funding.

Who has reviewed the study?
This study has been reviewed by the Research Committee at the School of Health and Social Care.

The LIMBIC project was given a favourable ethical opinion for conduct in the NHS by the Somerset Research Ethics Committee through the National Research Ethics Service, a division of the National Patient Safety Agency.

This further research project involving interviews with the patient representatives from the LIMBIC project has been given a favourable approval by the same Ethics Committee as a substantial amendment.

Thank you very much for taking the time to read this information sheet and considering whether or not to take part in this study.

Bournemouth
University

December 2008

Dear INSERT NAME

**Invitation to participate in an interview for a research study:
the LIMBIC project (Learning to improve the management of back pain in
primary care)**

Thank you for your participation in the Workshops for the LIMBIC project
which have been running during 2008 and for your contribution as a co-
researcher with the Practice teams involved.

I would now like to invite you to participate in an interview with myself, the
researcher for the LIMBIC project.

The purpose of this proposed interview is to seek a deeper understanding of
the patient representative experience in this piece of research. The interview
would take place after the final workshop and will last approximately one hour.
Depending upon the findings of the interviews with patient representatives, it
is possible that a further follow up interview will be carried out one year later
(December 2009/January 2010).

Enclosed with this letter is;
- An information sheet giving details of the study. Please read this.
- A consent form which I will ask you to sign after you have read the
  information sheet.

I will call you one week after the date on this letter to ask if you are interested
in participating and whether you have any questions.

Kind regards

Louise Worswick
Researcher
01202 962050 or 07515189799

Appendix 6

Researcher training

Researcher training, CPD and conferences

November 2007 – September 2013

Bournemouth University Postgraduate Researcher training programme

October 2008 to May 2009
Research Methodology and Skills Programme for postgraduate researchers

Graduate School Annual Postgraduate Researcher Conferences 2008, 2009, 2011

25-27 January 2010
Introduction to Education Practice for Research Students

22-23 October 2010
Focus Group Master Class

17 March – 8 April 2011
Introduction to statistics using SPSS

8-9 November 2012
Systematic Reviews Master class

14 – 15 January 2013
NVivo Qualitative data analysis two day training course

Study Days and short courses

29 November 2007
The future of service user involvement in research: funding and support
NHS Research and Development Forum

July 2007 to April 2009
Leading Improvement Teams
Improvement Foundation Leadership and Development Programme

25 May 2011
Accessing the NHS for research – A quick guide to regulatory requirements
Centre for Postgraduate Medical Research and Education, Bournemouth University

4 July 2011
Centre for the Advancement of Interprofessional Education (CAIPE) Student
Conference - Championing Interprofessional Education and Collaborative Practice
Southampton University

20 October 2011
Educating for Patient and Public Involvement (PPI) – Half day PPI summit
Institute for Leadership and Service Improvement, London South Bank University

9 November 2011
Introduction to Good Clinical Practice (GCP): A practical guide to ethical and scientific quality standards in clinical research
National Institute for Health Research (NIHR) Clinical Research Network Coordinating Centre, Yeovil Academy

12 February 2013
NIHR Workshop on Research into Primary Care Interventions
Church House Conference Centre, Westminster, London

Conferences attended

11-12 November 2008
INVOLVE 6th National Conference, Public Involvement in research, Getting it right and making a difference. A unique forum for people who are interested in active public involvement in research
East Midlands Conference Centre, Nottingham
Co-presentation - LIMBIC project service user involvement

6 April 2010
Folk.Us User Involvement Conference,Turning the Tide, Exeter University, Devon
Poster presentation with service users

24 June 2010
CAIPE AGM, London
Louise Worswick - Student poster competition – winner

16-17 November 2010
INVOLVE 7th National Conference, Nottingham, East Midlands Conference Centre
Paper (DVD) presentation: Louise Worswick and a service user

7-8 June 2011
Health Services Research Network – Service Development Organisation joint network conference, Liverpool
Poster presentation:
Louise Worswick, Eloise Carr, Charles Campion-Smith, Peter Wilcock, Alan Breen.
Learning about quality improvement in interprofessional teams – improving primary care management of back pain

13-14 November 2012
INVOLVE 2012 Conference – Putting people first in research
East Midlands Conference Centre, Nottingham
Poster presentation:
Louise Worswick, Chris Little, Kath Ryan, Eloise Carr
Involving service users as co-learners in research about quality improvement, interprofessional education and back pain: the service user perspective

Appendix 7

Data Analysis Strategy

Data analysis strategy

Code	D1.1
Name	**Call for Proposals (LIMBIC Project)**
Description	The Health Foundation call for proposals for the Engaging with Quality in Primary Care Award Scheme. This call for proposals produced the outline of the bid for a funding award which led to the development of a research project called the LIMBIC project (Learning to Improve the Management of Back Pain in the Community). There are five relevant documents; • a Call for Outline Proposals, • a Specification for Full Applications, • Guidance on completing the application form, • Guidance about the evaluation of the scheme - Your participation in evaluating an a Award Scheme and • a set of Frequently asked Questions.
Source	Accessed from the Programme Manager of the Engaging with Quality Scheme at the Health Foundation – via email and through personal contact with myself as researcher on the LIMBIC project
Type of data	Written report made available at the time of the call for proposals through the Health Foundation website www.health.org
Purpose for this study	To provide background information around the Engaging with Quality in Primary Care award scheme in relation to the role of the service user
Relevant research objective	To explore the extent to which the aims of the LIMBIC project, in relation to patient involvement, were met
Method of Analysis	I will seek to identify the Health Foundation Engaging with Quality in Primary Care Scheme objectives in relation to user involvement. I will do this by undertaking a content analysis of the documentation in order to try to increase my understanding of the intended purpose of user involvement in the overall award scheme. This will then help me to go on undertake evaluation of the user involvement approach which followed this stage of the bidding process.

Code	D.1.2
Name	**LIMBIC Project Research proposal**
Description	The Bournemouth University team proposal for a research project about improving the management of back pain in primary care submitted for the above (see D1.1) award scheme
Source	I had access to this document from my computer files in my role as project manager for the research project in question
Type of data	Written report and computer file Word document.
Purpose	a) To realise the intended aims of involving service users in the LIMBIC project b) To seek the nature of the input to the proposal from the perspective of the service user representative.

Relevant research objective	To explore the extent to which the aims of the LIMBIC project, in relation to patient involvement, were met;
Method of Analysis	Content analysis.
	The document will be reviewed with an approach to identifying the aims of involving service users in the project. It is anticipated that this will be explicitly made, and clearly described in the part of the document that describes the service user involvement aspect of the research. However it is possible that information about the aims of user involvement could appear anywhere in the document. Hence the full document will be studied.
	Taking into account (Silverman in Denzin & Lincoln 2003) that a document such as this one is a social production and may not be a transparent representation of organisational routine, or of decision-making processes. This is a document shaped by certain conventions and understandings (Denzin & Lincoln p56). In my role as project manager on the LIMBIC project I had an insight into this document that will allow a deeper understanding of its content as the terms used, processes described and the cultural approach will be familiar to me.
	Contrary to this is the fact that in depth knowledge of the project and the background information may lead to me giving a biased view of what I read and how I interpret what is written in the document. I will aim to take as neutral a stand as I possibly can and will give justification for any assumptions and conclusions that I make.

Code	D1.3
Name	**An evaluation of the Health Foundation's Engaging with Quality Initiative Second Annual Report**
Description	This report on the Engaging with Quality scheme which preceded the Engaging with Quality **in Primary Care** Scheme was produced by an external evaluation team, RAND Europe. A formal evaluation by an external evaluator (RAND) formed part of the evaluation of the LIMBIC project and this document outlines the evaluation approach taken by RAND.
Source	RAND Europe (see glossary) through contact with the RAND consultant through my role as LIMBIC project manager
Type of data	Written report and computer file Word document
Purpose in relation to this study	To help me gain insight into the design of the external evaluation of the LIMBIC project from the perspective of the external evaluator
Relevant research objective	To explore the extent to which the aims of the LIMBIC project, in relation to patient involvement, were met.
Method of Analysis	This report would help to contextualise the social world for the study, providing insight into the setting and the rules of engagement for award holders and their research participants. Emerging from an organisation, the document provided data about the social context. There was information about the approach taken to evaluation of the Engaging with Quality Scheme and so the overall evaluation process.

Code	D1.4
Name	**Supporting information for patients and practices**
Description	The research team put together a pack of support information to help both patients and practices in their task of recruiting and working with a patient representative
Source	LIMBIC project computer files and the project wiki
Type of data	Word documents
Purpose in relation to this study	To gain insight into the content of the supporting information provided by the research team for both patients and practices in their patient involvement activity
Relevant research objective	To analyse the existing data from the LIMBIC project that reflect the patient representatives' experiences and undertake further analysis where relevant
Method of analysis	These data were analysed as other documents related to the LIMBIC project which provided further context to the social world of the study. Comparison with the other sources including some of the narrative accounts from participants would help to capture the dynamic of the project as it evolved. The documents were explored for their relevance about the information which had been provided for participants at the outset of the project in order to gain an impression of the influences on their expectations and possible interpretations of their experiences of participating in the project as patient representatives.

Code	D2.1.1
Name	**Patient stories**
Description	Narrative accounts of the patient representatives' experiences of care and treatment for their condition presented by the patient representatives at Workshop Three.
Source	Directly received from patient representatives and also posted on the wiki. Patient representatives gave their permission to share these accounts through postings on the wiki.
Type of data	Documents and web postings. Six of the patient representatives had provided their personal stories which were read out at Workshop Three and which were subsequently posted on the project wiki.
Purpose in relation to this study	To deepen my understanding of the patient experience of back pain and potentially further illustrate the patient representatives' experience of being involved in the LIMBIC project.
Relevant research objective	To analyse the existing data from the LIMBIC project that reflect the patient representatives' experiences and undertake further analysis where relevant; To analyse the extent to which user involvement processes

	had an impact on the LIMBIC project outcomes
Method of Analysis	These written accounts were patient stories, they were biographical accounts of their experiences relating to their clinical condition and how it affected their lives. Using an inductive analytical approach to each of the individual patient stories I searched for patterns in the data to allow for codes and categories to emerge which might cross to other sources and other cases and contribute to the study findings.

Code	**D2.1.2**
Name	**Workshop material**
Description	Presentations and handouts from the workshops
Source	LIMBIC project computer files
Type of data	Power point presentations and handouts given to all the workshop participants plus a number of Word documents.
Purpose in relation to this study	To contribute to an interpretation of the events around the LIMBIC workshops, and capture the dynamic of the situation at the time.
Relevant research objective	To analyse the extent to which user involvement processes had an impact on the LIMBIC project outcomes
Method of Analysis	These documents did not represent raw data from the research but exploring the content and comparing with other data sources added to the contextualisation of the LIMBIC project and therefore the patient representative experience.

Code	**D2.1.3**
Name	**Workshop Fast feedback Forms**
Description	Fast feedback evaluation forms completed by all participants at the end of each workshop
Source	LIMBIC project computer files and hard copy files
Type of data	Self completed feedback forms – Original paper copies for each participant for each workshop Computer file copies of the fast feedback summary for each workshop, accumulating all participants feedback – Word documents
Purpose in relation to this study	To explore the feedback that was gained from all participants about their experience of each workshop immediately after each workshop event and to capture any data that might reflect their experience
Relevant research objective	To analyse the existing data from the LIMBIC project that reflect the patient representatives' experiences and undertake further analysis where relevant; To analyse the extent to which user involvement processes had an impact on the LIMBIC project outcomes;
Method of Analysis	Thematic analysis was undertaken of eight fast feedback reports. Categories were identified and subsequently compared to categories from other data sources to contribute to the development of themes.

Code	D2.1.4
Name	**Transcripts of focus group interviews with practice teams**
Description	Transcripts of pre and post workshop focus group sessions with practice teams
Source	LIMBIC project computer files
Type of data	Digital voice files and transcripts of voice files – Word documents
Purpose in relation to this study	To explore the experiences and expectations of patient representatives and practice teams prior to workshops and feedback after workshops
Relevant research objective	To explore the experiences of patient representatives involved in a specific primary health care research project; To analyse the existing data from the LIMBIC project that reflect the patient representatives' experiences and undertake further analysis where relevant; To analyse the extent to which user involvement processes had an impact on the LIMBIC project outcomes;
Method of Analysis	A thematic analysis of all the focus group data had already been undertaken for the LIMBIC project evaluation. I explored the findings from the analysed data as well as the raw data to search for categories and codes which might compare with those already identified through other sources. I tried to approach these data looking at them from the patient representative. I looked particularly for data relating to the experience of the patient representatives, their involvement, their actions and their words.

Code	D2.1.5
Name	**Interim review reports**
Description	Report of discussions with those participants who joined the project after the pre-workshop focus groups had taken place. This had been undertaken to determine early expectations of these participants who had not been able to participate in a focus group due to the timing of their entry into the project.
Source	LIMBIC project computer files
Type of data	Notes of phone calls, emails and meetings – Word documents
Purpose in relation to this study	To explore the expectations and experiences of patient representatives in relation to their role in the project
Relevant research objective	To explore the experiences of patient representatives involved in a specific primary health care research project
Method of Analysis	I undertook the analysis of these data when I analysed the patient specific data. Taking a thematic approach to analysis, I searched for all the documentation for comments made by patient representatives in their feedback and

	discussions and explored these data in context alongside the interview data and other patient specific datasets.

Code	D2.1.6
Name	**Wiki**
Description	Content of the project wiki
Source	www.wetpaint.limbic.com
Type of data	Wiki containing reports of improvement projects, photographs of project events and threads posted containing users' comments
Purpose in relation to this study	To observe the engagement of participants with the wiki and the nature of their discussions and input
Relevant research objective	To analyse the existing data from the LIMBIC project that reflect the patient representatives' experiences and undertake further analysis where relevant;
Method of Analysis	These data contributed to the contextualisation of the social world of the patient representatives and I explored them to seek insight into their contribution. Categories were compared to other sources of data. Thematic analysis of the material on the wiki which had been placed there by patient representatives plus analysis of the content of all the pages of the wiki was undertaken to extract and further analyse that which related to the patient experience. These data would contribute towards building a picture of the patient representative experience.

Code	D2.1.7
Name	**Practice team improvement project work**
Description	Summary report of the experiences of the practice teams and patient representatives who participated in the practice improvement projects.
Source	LIMBIC project Quality Improvement Facilitator's record of practice improvement projects
Type of data	Report of each practice team's improvement projects set up and monitored by the Quality Improvement Facilitator
Purpose in relation to this study	To explore the extent to which patients were involved in the practice improvement projects and any impact on the project outcomes and to explore their experience of being involved in the practice improvement projects
Relevant research objective	To explore the experiences of patient representatives involved in a specific primary health care research project; To analyse the existing data from the LIMBIC project that reflect the patient representatives' experiences and undertake further analysis where relevant; To analyse the extent to which user involvement processes had an impact on the LIMBIC project outcomes;
Method of Analysis	I undertook analysis of these data as I drew together all the patient-specific data at Stage Two of the analysis process. I

	interrogated the content of the reports drawing out of each practice improvement project report the data related to patient representatives' input and any comments made by the practice teams about patient involvement.

Code	D2.1.8
Name	**Patient representative pre-workshop meetings**
Description	Notes and action points from the patient representative group meetings which preceded the workshops
Source	LIMBIC computer data files – Word documents. Reports of the meetings posted on the LIMBIC project Wiki
Type of data	Power point presentation from Workshop One Written notes from Workshops Five, Seven and Eight
Purpose in relation to this study	To explore the issues that were important for patients and any content that was relevant to their experience of their involvement
Relevant research objective	To explore the experiences of patient representatives involved in a specific primary health care research project; To analyse the existing data from the LIMBIC project that reflect the patient representatives' experiences and undertake further analysis where relevant;
Method of Analysis	Exploration of the Word documents to identify data which documented the experiences of the patient representatives and then coding and categorising these data and integrating them into the data pool.

Code	D2.1.9
Name	**Emails, notes from phone calls, correspondence notes.**
Description	Written notes from phone calls, one-to-one conversations, ad hoc email correspondence and interim review dialogue
Source	LIMBIC computer data files
Type of data	Written notes – Word documents Hard copy prints of email correspondence
Purpose in relation to this study	To explore comments and views of patient representative participants of the LIMBIC project at various stages throughout the course of the project.
Relevant research objective	To explore the experiences of patient representatives involved in a specific primary health care research project; To analyse the existing data from the LIMBIC project that reflect the patient representatives' experiences and undertake further analysis where relevant;
Method of Analysis	Exploratory content analysis of a variety of documents related to communication with patient representatives during the course of the LIMBIC project.

Code	D2.1.10
Name	**Reflections on the Workshops**
Description	Reflections from all participants on their experience of the workshops, an exercise undertaken at the final workshop using a series of reflective prompts put together by the research team
Source	LIMBIC Project researcher computer files
Type of data	Paper copies of self-completed 'reflections' forms Computer word document versions of transcribed responses for each individual participant and team. Computer file Word document for the overall report. Summaries on the project wiki
Purpose in relation to this study	To capture the views of the patient involvement experience from the perspective of all workshop participants including practice teams and patient representatives
Relevant research objective	To explore the extent to which the aims of the LIMBIC project, in relation to patient involvement, were met; To explore the experiences of patient representatives involved in a specific primary health care research project; To analyse the existing data from the LIMBIC project that reflect the patient representatives' experiences and undertake further analysis where relevant; To analyse the extent to which user involvement processes had an impact on the LIMBIC project outcomes;
Method of Analysis	A thematic analysis of the content of the feedback provided on the individual forms was carried out.

Code	D2.1.11
Name	**LIMBIC photo gallery**
Description	Digital photographs were taken as various points throughout the course of the project and these were posted on the project wiki in a photo gallery
Source	LIMBIC project wiki
Type of data	On line digital photographs
Purpose in relation to this study	To capture visual data from the perspective of all workshop participants including practice teams and patient representatives
Relevant research objective	To analyse the existing data from the LIMBIC project that reflect the patient representatives' experiences and undertake further analysis where relevant;
Method of Analysis	Visual appreciation of the photographic images to add context to the social world of the patient representatives and capture the dynamic of the situation at the time of the workshops

Code	D2.2.1
Name	**Learning event**
Description	Input to the learning event around commissioning including the development of a patient focussed balanced set of outcome measures based upon the clinical value compass (Nelson et al 1996).
Source	LIMBIC project researcher computer files
Type of data	a) Written report of meeting b) Power point presentations c) Patient value compass as an output of the event – Word document diagram transcribed from original flip chart page. This was based on the Clinical Value Compass which is used to measure outcomes and aims to provide a balanced set of outcome measures.
Purpose in relation to this study	To explore the role of patient representatives in dissemination activities of the LIMBIC project, and their potential role in influencing the process of commissioning health services
Relevant research objective	To explore the extent to which the aims of the LIMBIC project, in relation to patient involvement, were met; To explore the experiences of patient representatives involved in a specific primary health care research project; To analyse the existing data from the LIMBIC project that reflect the patient representatives' experiences and undertake further analysis where relevant; To analyse the extent to which user involvement processes had an impact on the LIMBIC project outcomes;
Method of Analysis	Exploration of the data to seek insight into the relative significance for this research, search for categories and codes that identify patterns and similarities across other data sources. Blend relevant data into the thematic analysis.

Code	D2.2.2
Name	**LIMBIC film – A Day at the Races**
Description	LIMBIC project participants including patient representatives acted out key roles in the LIMBIC film
Source	LIMBIC website http://www.limbic.org.uk/story.html A DVD copy of the film is also available.
Type of data	Online film and DVD
Purpose in relation to this study	Observe the role taken by patients in re-enacting the LIMBIC journey
Relevant research objective	To explore the experiences of patient representatives involved in a specific primary health care research project; To analyse the existing data from the LIMBIC project that reflect the patient representatives' experiences and undertake further analysis where relevant;
Method of Analysis	Transcription of the dialogue from the film followed by thematic analysis of the transcript.

Code	D2.2.3
Name	**LIMBIC illustration**
Description	Patient representatives and other LIMBIC project participants on the filming day were subjects captured in an illustration of the LIMBIC journey. This output is a copy of an original illustration by a professional strategic illustrator.
Source	LIMBIC project outputs store The illustration is also used on the LIMBIC website http://www.limbic.org.uk in "Learn about the LIMBIC project". A4 sized versions of the illustration were made to share as part of the dissemination processes for the LIMBIC project
Type of data	The original art work was undertaken using pastel on artist's paper and a copy of this has been made which is used for conference presentations and local displays showcasing the LIMBIC project.
Purpose in relation to this study	To capture the dynamic of the setting at the time of the project, to add context to the social world and to create a perception of the role of patients in the LIMBIC project as depicted by the strategic illustrator and therefore a visual re-creation of the LIMBIC workshops
Relevant research objective	To analyse the existing data from the LIMBIC project that reflect the patient representatives' experiences and undertake further analysis where relevant;
Method of Analysis	Exploratory visual analysis of the material using existing data as background and capturing the dynamic of the situation at the time of shooting the LIMBIC film.

Code	D2.2.4
Name	**Filmed interview about user involvement for the Health Foundation**
Description	One patient representative gave a filmed interview for The Health Foundation about her role in the LIMBIC project
Source	The film was posted on the Health Foundation website www.health.org.uk but has now been archived. It can now be found on the LIMBIC website http://www.limbic.org.uk/sufilm.html .
Type of data	Web-based film
Purpose in relation to this study	To explore the experience of patient involvement from the patient representative perspective.
Relevant research objective	To explore the experiences of patient representatives involved in a specific primary health care research project; To analyse the existing data from the LIMBIC project that reflect the patient representatives' experiences and undertake further analysis where relevant;
Method of Analysis	Transcription and thematic analysis of the film transcript

Code	D2.2.5
Name	**Celebratory and Dissemination event**
Description	Patient representatives celebrated the successes of the LIMBIC project along with other practice team members, the research team and stakeholders at the celebratory and dissemination event in September 2009
Source	Researcher's LIMBIC project computer files
Type of data	a) Flyer, programme and delegate list from the event b) Power point slides of presentations c) Photographs taken at the event d) Evaluation report from delegate feedback – Word document e) Written report of the event – Word document
Purpose in relation to this study	To gain a deeper understanding of the experience of patient involvement and to capture the experiences of patient representatives at a particular time in the project.
Relevant research objective	To explore the extent to which the aims of the LIMBIC project, in relation to patient involvement, were met; To explore the experiences of patient representatives involved in a specific primary health care research project; To analyse the existing data from the LIMBIC project that reflect the patient representatives' experiences and undertake further analysis where relevant; To analyse the extent to which user involvement processes had an impact on the LIMBIC project outcomes;
Method of Analysis	Exploration of the data to seek insight into the relative significance towards the research followed by exploration of datasets to observe codes, categories, patterns and themes.

Code	D2.2.6
Name	**Conference posters and presentations involving LIMBIC patient representatives**
Description	Contribution to abstracts for posters and presentations at conferences; a) INVOLVE Conference 2008 – poster presentation b) Folk.Us User Involvement Conference 2010 – poster presentation c) LIMBIC Master class for Primary Health Care Teams 2010 – oral presentation d) INVOLVE Conference 2010 – workshop presentation e) Authenticity into Action 'Rhetoric or Reality' Conference, University of Central Lancashire – June 2011- Showcase presentation
Source	Conference abstracts and researchers reports and reflective accounts of the conferences – Word documents on researcher's computer.
Type of data	Conference poster (a) pdf computer files (a)

	Illustration – copy of original art work (b) Film of educational event and transcript (Word) – Master class (c) Word document of reflective account (d, e)
Purpose in relation to this study	To seek insight into the experience of patient involvement in relation to the events disseminating the findings of the LIMBIC project.
Relevant research objective	To explore the extent to which the aims of the LIMBIC project, in relation to patient involvement, were met; To explore the experiences of patient representatives involved in a specific primary health care research project; To analyse the existing data from the LIMBIC project that reflect the patient representatives' experiences and undertake further analysis where relevant; To analyse the extent to which user involvement processes had an impact on the LIMBIC project outcomes;
Method of Analysis	Exploration of data for relevance to the research and capture of codes, categories and themes which relate to themes that have been identified and comparison with other sources

Code	D2.2.7
Name	**Papers and publications**
Description	Publications and articles co-written with patient representatives
Source	a) BackCare Journal for Healthcare professionals – November 2009 – from BackCare b) BackCare members bulletin October 2009 – from BackCare c) Involve Newsletter Article January 2011 d) Sunday Telegraph Supplement 27 September 2009– personal copy
Type of data	a) National Charity Journal for healthcare professionals – hard copy and pdf computer file b) National Charity member's bulletin – hard copy and pdf computer file c) E-newsletter d) Newspaper
Purpose in relation to this study	To help gain further understanding of the patient experience of involvement from the patient perspective
Relevant research objective	To explore the experiences of patient representatives involved in a specific primary health care research project; To analyse the existing data from the LIMBIC project that reflect the patient representatives' experiences and undertake further analysis where relevant; To analyse the extent to which user involvement processes had an impact on the LIMBIC project outcomes;
Method of Analysis	Exploration of data to determine content which related to existing themes and any further categories or codes

Code	D2.2.8
Name	**Advising health service commissioners**
Description	Patient representatives offered their expertise as consultants to other organisations and groups wishing to engage with patients, for example, commissioning back pain services in line with newly released NICE guidelines for management of sub-acute low back pain.
Source	The documentation was accessed at the event and a subsequent report of the meeting was accessed from the neighbouring academic institution which hosted the commissioning event.
Type of data	Written evaluation report of meeting, Programme for the event and hand-out from Power point presentations
Purpose in relation to this study	Exploring the patient representatives' experience of their contribution to a meeting about commissioning
Relevant research objective	To explore the experiences of patient representatives involved in a specific primary health care research project; To analyse the existing data from the LIMBIC project that reflect the patient representatives' experiences and undertake further analysis where relevant; To analyse the extent to which user involvement processes had an impact on the LIMBIC project outcomes;
Method of Analysis	Exploratory content analysis of the documentation as part of the thematic analysis.

Code	D3.1
Name	**Semi structured interviews**
Description	Semi structured interviews with the patient representatives
Source	Researcher computer voice files and transcripts
Type of data	Digital voice files and interview transcripts - Word documents
Purpose in relation to this study	To gather primary data from patient representatives about their experience during their engagement with the LIMBIC project.
Relevant research objective	To explore the experiences of patient representatives involved in a specific primary health care research project; To analyse the extent to which user involvement processes had an impact on the LIMBIC project outcomes;
Method of Analysis	Thematic analysis of the transcripts of the interviews. Initially I used a whole text analysis approach towards coding of the data from the interview transcripts. I read the transcripts prior to coding by assigning codes to fixed units of text – sentences or paragraphs that related to a particular topic. I attempted to apply codes to all of the text in all of the transcripts. Constant comparison of the data, working back and forth between the data and the coding system, I looked for recurring regularities and deviant cases in the data. Eventually I observed a number of themes which linked

	together some of the codes and related them to each other.

Code	**D3.2**
Name	**Semi structured interview with a member of the LIMBIC research team**
Description	Research interview with one of the LIMBIC project Steering Group members
Source	Researcher's computer
Type of data	Digital voice file recording and interview transcript – Word document
Purpose in relation to this study	To gain further insight into the experience of the patient representatives from another perspective - that of the facilitator of the patient representative group meetings
Relevant research objective	To explore the extent to which the aims of the LIMBIC project, in relation to patient involvement, were met; To analyse the extent to which user involvement processes had an impact on the LIMBIC project outcomes;
Method of Analysis	Thematic analysis as described in 3.1 above.

Appendix 8

Copies of LIMBIC illustration
(2 pages)

Glossary

This glossary contains definitions of the key terms used in this thesis and details of some of the organisations mentioned.

Definitions

In the context of this study, the following definitions are assumed.

Co-learner

The service users in the LIMBIC project who were patient representatives from their practice population were also co-learners. Rutherford's (2011) definition of co-learner is used in this thesis. Originally developed as a sensitizing concept and, combined with the definition of interprofessional education (Barr et al. 2002), this definition of co-learner contains the following elements:

- Learning with, from and about each other
- Sharing the roles of expert and novice, teacher, and learner
- Application and re-creation of knowledge
- Mutually beneficial processes for addressing issues of importance to all participants
- Active involvement in deciding what and how to learn.

Source: Rutherford, G., 2011.

Patient and Public Involvement (PPI)

This term for the involvement of patients in planning, delivering and evaluating health services is usually limited users of health services. Public involvement in the NHS focuses on the development and planning of healthcare services and on the operation and delivery of healthcare services, including the regulation of safety and quality, the competence of healthcare professionals, and the protection of vulnerable groups.

Source: http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/

Patient engagement

This term is a generic term used by healthcare professionals to mean engagement in one's own health, care and treatment.

Source: Parsons et al. 2010

Public involvement

The organisation, INVOLVE defines public involvement in research as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials, undertaking interviews with research participants.

Source: INVOLVE 2013 www.invo.org.uk

Service user involvement

Similar to the INVOLVE definition of public involvement, this term refers to involvement in a broader range of areas than research alone. It refers to the involvement of users in research, health service planning, delivery and evaluation of services and nowadays commissioning of services as well. It also refers to the involvement of patients in planning their care, in designing and delivering educational initiatives in higher education institutions, users of social services in planning their care and the involvement of children in planning school curriculae and students in universities.

Wiki

A wiki is a website or database developed by a group of users, in which any user is able to add and edit content.

Source: Compact Oxford English dictionary, 3rd edition revised, 2008, Oxford University Press, Eds. Soanes, C., Hawker, S.

Organisations

Health Foundation

A charitable Foundation working to improve the quality of healthcare across the UK and beyond.

Engaging with Quality Award Scheme
A funding scheme provided by the Health Foundation which aims to help healthcare professionals close the gap between current and best practice across clinical services

Engaging with Quality in Primary Care Scheme involves nine projects engaging primary care clinicians in the quality improvement process

Source www.health.org.uk

INVOLVE

INVOLVE is a national advisory body funded by the National Institute for Health Research to promote and support public involvement in NHS, public health and social care research and development.

Source www.invo.org.uk

RAND Europe

RAND Europe is an independent not-for-profit research institute whose mission is to help improve policy and decision-making through research and analysis. They are part of the global RAND corporation, known for delivering high quality, objective research and analysis for over 60 years

Source www.rand.org.uk