

The influences of patient-professional partnerships on the self-management of chronic back pain: a mixed methods study

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Peer-reviewed publications

1. **Fu Y.**, McNichol E., Marczewski K. & Closs S. J. Patient–professional partnerships and chronic back pain self-management: a qualitative systematic review and synthesis. *Health and Social Care in the Community*. (doi: 10.1111/hsc.12223).

The author of this thesis was the first and corresponding author for the above publication. She drafted the papers, revised as per supervisors' feedback, formatted according to the journal style, submitted to the respective journals, and addressed the comments raised by the editorial office, reviewers and the production office.

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Abstract

Background: The self-management of chronic back pain may be a lifetime task for many patients. Whereas health professionals are experts in providing health services to support patients, the pain itself and its impact can only be experienced by the patients living with it. It is likely that optimum self-management of chronic back pain may only be achieved when patients and professionals develop a good partnership that integrates their complementary knowledge and skills.

Aim: To explore patients' perceptions of the nature and influence of partnerships with health professionals, on their ability to self-manage chronic back pain. There were two objectives: the first was to assess the influence of patient-professional partnerships on patients' ability to self-manage chronic back pain and to identify any associations between them. The second was to explore patients' perceptions and experiences of the influence of these partnerships on their self-management ability.

Methods: First, a systematic review was conducted to identify research undertaken in this area and to identify key factors within patient-professional partnerships that may influence self-management. Second, an explanatory sequential mixed methods study was undertaken in three pain management clinics in Northern England, UK. Patients were recruited following an initial clinic consultation (baseline) and followed up after three months. The aim of the quantitative phase was to detect changes in outcomes (i.e. PIH, PPIc, BPI, HADS, PSEQ and DoloTest) between the baseline and follow-up data collection. Hierarchical linear regression was used to investigate the association between patient-professional partnerships and the self-management of chronic back pain. A complementary qualitative phase using grounded theory was then conducted through in-depth interviews with a purposive subsample of 26 of the patients from phase one. The aim was to explore patients' perceptions and experiences of the influence of patient-professional partnerships on their self-

management ability. Each interview was transcribed and analysed using constant comparative analysis.

Results: Seven themes were identified in the systematic review: communication, mutual understanding, roles of health professionals, information delivery, patients' involvement, individualised care and health care service. These were developed into a model suggesting how factors within patient–professional partnerships may influence the self-management of chronic back pain. One hundred and three (70.1%) patients completed both baseline and follow-up data collection. Patients' self-management ability, partnerships with health professionals, pain interference, self-efficacy, general health, and anxiety disorder all showed statistically significant improvement at follow-up. Regression analysis showed that improvements in patient-professional partnerships were positively associated with improvements in pain self-management. In-depth interviews identified a range of facilitators of and barriers to a good patient-professional partnership. Five supportive approaches were provided by health professionals in the pain clinics. Patients' experiences suggested that a good partnership supported the development of their self-management ability.

Conclusion: A good patient-professional partnership appears to have a positive impact on patients' ability to self-manage their chronic back pain through five supportive approaches. The long term impact of the pain clinic could not be fully evaluated, and further research is needed to assess the effectiveness of pain management services of this kind.

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Lists of Abbreviations

BPI	Brief Pain Inventory
CASP	Critical Appraisal Skills Programme
CBT	Cognitive Behavioural Therapy
CPSS	Chronic Pain Self-Efficacy Scale
DH	Department of Health
EPP	Expert Patients Programme
ESCAPE	Evaluation of Stepped Care for Chronic Pain
GP	General Practitioner
GSE	General Self-Efficacy
HADS	Hospital Anxiety and Depression Scale
IMMPACT	Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials
IRAS	Integrated Research Application System
MPI	Multidimensional Pain Inventory
NCM	Nurse Care Manager
NHS	National Health Service
NRS	numerical rating scales
PIH	Partners in Health scale
POMS	Profile of Mood States
PPiC	Patient Partnership in Care
PSEQ	Pain Self-Efficacy Questionnaire
QoL	Quality of Life
R&D	Research and Development
RCT	Randomised controlled trial
SD	Standard Deviation
TENS	Transcutaneous Electro-Nerve Stimulator
UK	United Kingdom
US	United States
VAS	Visual Analogue Scales
VRS	Verbal Rating Scales
WHO	World Health Organisation

Chapter 1 INTRODUCTION

This thesis is a report of the research undertaken during a PhD study in the School of Healthcare at the University of Leeds. This study explores how patient-professional partnerships influenced patients' self-management ability for chronic back pain. It assesses whether there were any changes in patients' conditions and other pain-related outcomes after their attendance at the pain management clinic, and identifies any associations between patient-professional partnerships and the self-management of chronic back pain. Based on these results, this study further explores patients' perceptions and experiences of the influence of these partnerships on their ability to self-manage the pain.

This chapter starts with a descriptive account of the author's background and location in this thesis. Following this it provides a brief overview of the characteristics of chronic back pain and its self-management, and the implementation of patient-professional partnerships in the health care setting. Finally, a section detailing a brief discussion of the thesis structure and writing style is included.

1.1 Personal location

This section has been included to enable the context in which this study was undertaken to be visible, and also to inform the reader of the path that has led me to this position.

My interest in patient-professional partnerships originated through reflection on the internship that I undertook during the last year of my Medicine degree in China. The medical care system in China is different from that in the United Kingdom (UK). Although patients in China can choose which hospital or doctor they prefer to visit, they need to provide payment for the service and treatment received. Under the current system the majority of the population of China have basic health insurance

provided by their employers (or ex-employers if retired); although, out-of-pocket costs and the quality of care varies significantly. I worked as a medical intern in Henan Provincial People's Hospital, which is the largest hospital in the province of Henan. This hospital has a total of more than 8,000 sick beds. I worked in almost all the departments, expecting to gain experience, learn practical skills and apply my medical knowledge to the patients. However, during my routine work I found that the relationship between patients and the medical staff (i.e. doctors and nurses) was often not smooth. On many occasions patients and their carers did not seem satisfied with the level of service or care provided by doctors or nurses and always expected more, while medical staff were facing hundreds of patients every day, and we felt that we were already providing the best level of service and care for them. It was not surprising to encounter people arguing occasionally. As an inexperienced medical intern, I started to reflect on my practice in this hospital and to observe the behaviour of both patients and health professionals. This enabled me to realise that there was a lack of sufficient communication and mutual understanding. The medical staff might not fully understand patients' personal backgrounds and, therefore, did not implement individualised care due to a large number of patients and limited time (the patients per doctor ratio is 950:1 in China (Jacobs, 2007)). Their focus when treating a patient was solely on the health problem, and they did not take into account any aspects of the patient's emotional needs. Patients often received inadequate explanations of their conditions as well as limited information on what treatment options were available to them and how to choose the most appropriate one. I realised that poor communication between patients and medical staff led to poor relationships.

As a researcher with a medical background, I have always believed that communication makes complicated situations easier and is a direct approach that permits an understanding of what other people expect. In line with this I feel that communication between patients and medical staff should be a fundamental principle,

enabling them to work together toward a common goal: effectively managing health problems. Holding on to this belief, I started my overseas learning journey with a Master's in Public Health at the University of Sheffield in the UK in 2010 with the aim of gaining more insight into the British National Health Service (NHS) and to experience a different lifestyle. Having completed my Master's degree and final dissertation on 'Patients and the Public Involvement', I was keen to use and expand my knowledge to start my PhD journey while concentrating on patients and health professionals' partnerships. During the interview for PhD funding, I presented this research topic that focused on long term conditions. I felt that this prospective research study would not only facilitate me as an independent researcher but also enable me to accumulate substantial experience of conducting research within the university and the NHS.

1.2 Chronic back pain

Chronic pain is defined as a continuous, unpleasant experience that occurs for more than 12 weeks or past the time that healing would have been thought to have occurred in pain after trauma or surgery (British Pain Society, 2013). The prevalence of chronic pain is increasing, globally (Vos et al., 2013). Primary care settings in the Americas, Asia, Europe and Africa report a prevalence of 10% to 25% of patients with chronic pain (Breivik et al., 2006; Johannes et al., 2010; Reid et al., 2011). This prevalence increases with advancing age and poor socioeconomic status, and it tends to be more frequent in females (Croft et al., 1998). For example, in the United States (US) prevalence for females is 34.3%, which is higher than for males (26.7%). Similarly, 37% of females and 31% of males in the UK reported the occurrence of their chronic pain (Health and Social Care Information Centre, 2011).

Chronic back pain has been identified as the most common type of chronic pain and is often caused by spine movement, spine injuries and the wearing down of the facet

joints (National Institute of Neurological Disorders and Stroke, 2014). The impact of chronic back pain on both the individual, industry and society is substantial (Jacobson and Mariano, 2001). Patients often experience considerable discomfort, and their family and social relationships are interrupted (Hunfeld et al., 2001). Many report that they are less able or no longer able to participate in various daily activities because their pain increases as a result of their activity. Chronic back pain also severely affects their sleep pattern and ability to exercise, do household chores, attend social activities and maintain an independent lifestyle (Breivik et al., 2006). In addition, many studies explore the association between chronic back pain and psychological disorders, including anxiety, depression, low mood and negative body image. In manual labour jobs back pain causes the largest absence from work in the UK (NHS Choices, 2013). Sixteen per cent of patients with chronic back pain who are absent from work are still not working after one year (National Collaborating Centre for Primary Care, 2009). A recurrence of chronic back pain is also highly likely. According to Pengel et al. (2003), the risk of at least one recurrence in patients is 73% within a 12-month period. However, patients often struggle to receive adequate management for their condition or even a diagnosis. For most patients, there is no cure that can relieve the pain permanently (Baker et al., 2010), and they often spend many years seeking help and sometimes get stuck in a cycle of visiting different health professionals (Clare et al., 2013). As a result, the NHS invests an estimated 12.3 billion pounds per year in chronic non-malignant back pain alone (Health and Social Care Information Centre, 2011). Due to the high prevalence, deleterious impact and lack of any guaranteed cure, chronic back pain has become a major clinical, social and economic health problem (Smith et al., 1999; Phillips, 2008; Croft et al., 2010), and it is one of the top 10 diseases and injuries that account for the highest number of disability – adjusted life years worldwide (Vos et al., 2013).

1.3 Self-management of chronic back pain

Although efforts have been made to help patients cope with the pain as well as its impact, for example, providing treatment and setting up an online forum for patients to share their views on their conditions, health outcomes are often not quite satisfactory (Department of Health, 2013a). Of all the methods used by patients to control pain, for example, medication, massage and Transcutaneous Electro-Nerve Stimulator (TENS), self-management is believed to be central to the control of pain and related functional problems (The Centre for Managing Chronic Disease, 2011). Self-management of chronic back pain is defined as “an ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition individually” (Barlow et al., 2002 p.178). Good self-management ability involves changes in patients’ behaviour, better use of medicines and treatment of minor ailments and better care of long term conditions. It also includes staying fit and healthy, taking action to prevent illness and accidents (Scottish Executive, 2007). An important concept in self-management is self-efficacy, which refers to one’s confidence to undertake the behaviour necessary to achieve a desired goal (Bandura, 1997). Self-efficacy reflects patients’ abilities to organise and integrate skills in the self-management of chronic back pain (Bandura, 1986; Bandura and McClelland, 1977; Bandura, 1997; Yoo et al., 2011; Dures and Hewlett, 2012). There has also been growing interest in establishing supportive organisations and initiating health policies on the self-management of chronic conditions. The Department of Health (DH) reiterates that people have better lives when they take care of their conditions themselves, supported by skilled health professionals (Department of Health, 2006b). In the DH White Paper *Our Health, Our Care, Our say*, ‘helping people take control’ is presented as a key theme (Department of Health, 2006a). It focuses on supporting self-management for people with long term conditions as well as helping individuals

manage their own care better by creating continuity for supported self-management, and delivering courses on self-management to meet patients' health needs.

Many self-management programmes have been developed worldwide to support patients in self-managing their chronic back pain. These programmes are considered to be a path towards seeking better solutions to illness and are believed to be beneficial not only for patients looking to manage their symptoms and gain control over their lives, but to society as a whole to reduce health care time and costs (Gurden et al., 2012). The fundamental principle of these programmes is to deliver skills for patients and to encourage patients' involvement with health professionals in developing their treatment or care plans together (Lorig and Holman, 2003). One well-known programme is the Arthritis Self-Management Program by Lorig (1986), which has been identified as a standardised self-management programme and also a major contributor to the global pain self-management effort. Barlow et al. (2000) tested a similar programme in the UK. Participants in the intervention group were given information about arthritis, self-management strategies, exercise, skills for depression management, communication with health professionals and setting realistic goals. The results showed a decrease in pain, depression and fatigue, and a high degree of self-efficacy and cognitive symptom management in the intervention group. Meanwhile, positive moods, better communication with physicians, relaxation skills and exercise activities were significantly greater among the intervention group. Compared with passive dissemination of patient education which solely focuses on disease-specific solutions, self-management emphasises the development of patients' skills, aiming to enhance self-efficacy in the control of pain symptoms to maintain a healthy lifestyle (Lorig et al., 1999; Bodenheimer et al., 2002).

In practice, self-management programmes for chronic back pain have a considerable positive impact on patients' health outcomes. For instance, these programmes not only provided patients with useful skills and enabled them to experience better health,

wellbeing and co-ordinated care, but also helped patients reduce their perceived severity of the pain, building up greater confidence and improving mental health (Von Korff et al., 1998; Von Korff and Moore, 2001; Damush et al., 2003; Von Korff et al., 2005; Department of Health, 2006b; Dixon et al., 2007). Self-management of chronic back pain also has a positive impact on the use of health service. For example, when patients practise self-management skills, they are more likely to prevent the need for emergency health and social services and unnecessary hospital admissions. This may reduce the number of visits to general practitioners (GPs) and outpatient clinics and may reduce drug expenditure (Kennedy et al., 2004; Robinson et al., 2006; Department of Health, 2006b; De Silva, 2011). One study suggests that self-management compared with usual care is cost-effective for chronic back pain when measured in terms of cost per quality-adjusted life years gained (Lamb et al., 2010).

Furthermore, dissemination of self-management programmes may enhance the overall partnership between academic researchers and other key stakeholders (Lorig et al., 2005; Bruce et al., 2007). Most self-management interventions are designed and piloted within an academic environment aligned with a variety of hospital and community-based settings. Consequently, delivering these interventions into existing and diverse system infrastructures may result in collaboration. Therefore, greater cooperation is needed between organisations such as local authorities to work together with the community and the voluntary and private sectors (Department of Health, 2006b).

As chronic back pain is a long term condition, self-management may be a lifetime task for most patients. Whereas health professionals are experts in providing health services to support patients (Coulter and Ellins, 2007; May, 2010), the pain itself and its impact can only be experienced by the patients living with the condition. It is likely that optimum self-management of chronic back pain may only be achieved by both patients and health professionals working in partnership.

1.4 Patient-professional partnerships

A parallel development to the self-management of chronic pain is the transition from the concept of paternalistic health care to an emphasis on establishing partnerships between patients and health professionals (Barlow et al., 2002). The World Health Organisation (WHO) suggests that the effective management of chronic pain requires health care services to be patient-centred (WHO, 2002). In the UK, the NHS Executive (1999) highlights the importance of promoting patients' involvement in their own health care as active partners with health professionals, which has also been identified as being fundamental to the aim and purpose of rehabilitation (Leach et al., 2010). The NHS Plan (NHS Executive, 2000) states that patients must have more say in their treatment and be able to work with and influence how the NHS is working. The NHS should support patients in self-management through a partnership that helps them make decisions and take action to manage their pain (Department of Health, 2006b).

Previous research also supports the notion that self-management is dependent on partnerships between patients and health professionals (Bodenheimer et al., 2002). A partnership is defined as "a co-operation or an alliance where people work together in mutual respect" (Enehaug, 2000 p.178). A core component of a patient-professional partnership is the inclusion of the patient as an active partner in their health care (Clark and Gong, 2000; Holman and Lorig, 2000; Davies et al., 2000; Turner and Kelly, 2000). Notably, a good partnership should be based on mutual respect and trust in each other's expertise, competencies and recognition of combined knowledge (Suchman et al., 1998; McQueen, 2001). A good partnership between patients and health professionals is essential, as it acts as the foundation of achieving every goal in patients' care plans, enabling the shared information and knowledge to be more individualised. Lorig and Holman (2003) suggest that forming a patient-professional partnership is a key element of effective chronic pain self-management. In addition,

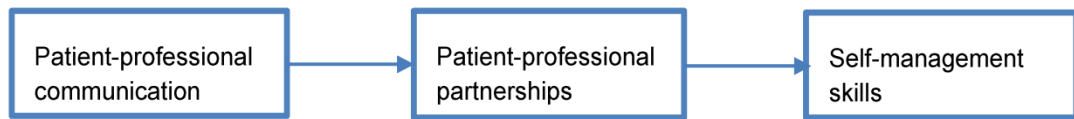
patients' experiences of living with chronic back pain are shaped through their biological, sociocultural and environmental contexts, which present a uniquely individual feeling (Brown, 2003). Patients can clearly understand their own pain, social circumstances, habits and behaviour, attitudes to risk, values and preferences. On the other side, health professionals have a different kind of knowledge, being well informed about diagnostic techniques, the causes of pain, prognosis, treatment options and preventive strategies (Coulter, 1999). Their understanding of chronic back pain is gained mainly from the descriptions from patients as well as their own beliefs about the condition. Patients and health professionals by working together and sharing their expertise and relevant information are more likely to generate a more appropriate and individualised self-management plan, which fits patients' health needs. If patients and health professionals work as equal partners, patients will develop new understandings and embrace new responsibilities for their health (Cooper, 2001). By taking patients' views, beliefs and expectations into consideration, health professionals will be better prepared to discuss patients' care plans and be able to provide more individualised information, attaining higher satisfaction, better compliance and greater continuity of care (Holman and Lorig, 2000; Stanley et al., 2013).

1.5 Patient-professional partnerships and self-management of chronic back pain

The importance of patient-professional partnerships in the self-management of chronic pain has been demonstrated in both practice and research. The Expert Patients Programme (EPP) was developed with the aim of combining the valuable work of patients and health professionals in developing self-management initiatives based on patient-professional partnerships (Department of Health, 2001). "Partnerships between patients and health professionals are essential" was highlighted as a key theme at the EPP Stakeholder Conference. It suggests that a

cultural change is needed to replace paternalism with partnership in health care settings (Department of Health, 2001 p.31). Moreover, contemporary pain management theories and models also suggest that a good patient-professional partnership enhances patients' ability to self-manage their condition in primary care (Bodenheimer et al., 2002; Wagner et al., 2005; Cooper et al., 2008; Coulter and Collins, 2011). Of these, a pathway model proposed by Street et al. (2009) illustrates the links between patient-professional partnerships and the self-management of chronic conditions (see Figure 1.1). In this model, patient-professional communication is presented as a fundamental factor influencing patients' self-management skills in an indirect way through the establishment of patient-professional partnerships. It also provides a theoretical explanation of how this indirect path by which health professionals' clear explanations and expressions of support could enable greater patient trust and understanding of treatment options. This could encourage patients to follow the practice of pain self-management. Patients' communication with health professionals could enable health professionals to have a better understanding of patients' health needs. Consequently, health professionals could identify their priorities and deliver care and services in a way that patients need or prefer. As a result, it is more likely that a mutual agreement and partnership will be established between patients and health professionals, underpinning the development of patients' self-management ability.

Figure 1.1 Pathway linking patient-professional partnerships and self-management



1.6 Thesis structure and writing style

In the context of the self-management of chronic back pain, the research work conducted and presented in this thesis progresses the understanding of how patient-professional partnerships may have an impact on the self-management of chronic back pain in primary care settings. This entire study took place between September 2012 to September 2015, and a total of 147 participants were recruited from SpineFit, Leeds Community Healthcare NHS Trust, UK. Of them, 103 patients completed both baseline and follow-up questionnaires, and 26 patients participated in individual face-to-face in-depth interviews. A brief summary of the contents of each chapter is provided in this section, enabling readers to gain a whole picture of this thesis and locate detailed information. A third-person objective style has been used throughout this thesis, except for the beginning of this chapter and in Chapter 7, where the first-person style is used in detailing the author's background and personal reflection. This introduction comprises Chapter 1, and the following chapters are described below.

Chapter 2: Literature review

This chapter explores existing literature on patient-professional partnerships and the self-management of chronic back pain, identifying key factors within these partnerships that may influence pain self-management. This provides the reader with a broader picture of the research undertaken in this field. Based on the knowledge gap identified in the literature review, the research aim and objectives of this study are proposed.

Chapter 3: Methodology

This chapter presents the research methodology and specific design used as the framework for this study, based on the research aim and objectives. An introduction of different research methodologies and how they underpin health care research is outlined. The selection of a mixed methods approach using explanatory sequential design is then justified in detail, leading to the proposal of a quantitative phase using quasi-experimental design. This is followed by a complementary qualitative phase using constructivist grounded theory for addressing the research objectives.

Chapter 4: Methods

This chapter details the methods chosen for the quantitative and qualitative phases. It starts with a description of the process of obtaining ethical and research governance approvals followed by the recruitment of patients, sample size calculation and data collection and analysis for both the quantitative and qualitative phases.

Chapter 5: Results of quantitative study

This chapter presents the results of the quantitative phase, including patients' socio-demographic and clinical characteristics, statistical tests and hierarchical linear regression. Tables and figures are used to enable a straightforward reading and understanding of the data.

Chapter 6: Results of qualitative phase

This chapter outlines the findings of the qualitative phase. It starts with the description of the socio-demographic and clinical characteristics of the interviewed patients. It then presents each theme and its related categories in detail. Anonymised quotes extracted from patient interviews are included to enable a rich understanding of each theme and category. Relationships between themes and categories are also explored, with particular emphasis on the influence of patient-professional partnerships on the development of the ability of pain self-management.

Chapter 7: Discussion

This chapter starts with a brief personal reflection on the author's learning experience during the writing of this PhD; it then interprets the findings from both the quantitative and qualitative phases. The integration of these two phases together with the findings of the literature review enables this study to provide an in-depth understanding of the influence of patient-professional partnerships on patients' self-management ability for chronic back pain. The limitations of this study and recommendations for future policy, practice and research are presented.

Chapter 2 LITERATURE REVIEW

2.1 Introduction

The existing literature on partnerships between patients and health professionals, and their impact on patients' ability to self-manage back pain are reviewed in this chapter. Firstly, the definitions of key terms used in the literature review are presented. The detailed manner in which the literature search and the synthesis was undertaken is described in the method section. A systematic literature search was employed in this review to ensure that as many relevant articles as possible were included. The results of this review are presented in two main sections: a critique of the included studies and themes that emerged from the thematic synthesis. Finally, the limitations and conclusion of this review are presented, leading to the research questions for this study.

2.2 Definitions

The condition that this review focuses on is chronic back pain. Health professionals refer to the people who could be involved in treating patients with back pain, including the pain specialist, GPs, psychologists, physiotherapists and specialist pain nurses (British Pain Society, 2010). The definition of self-management of chronic back pain and patient-professional partnerships given in Chapter 1 are consistently used here.

2.3 Review aim

There have been several reviews on either the self-management of chronic back pain (Du et al., 2011; Oliveira et al., 2012) or patient-professional partnerships (Ridd et al., 2009), but none that focused on both. How partnerships would influence a patient's ability to self-manage the pain still remains unknown. The lack of evidence led to the decision to undertake this systematic review. The aim was to explore the influence of patient-professional partnerships on patients' ability to self-manage chronic back pain,

identifying key factors within these partnerships that may influence self-management. The findings of this review provide both patients who have chronic back pain and health professionals, with an understanding of patient–professional partnerships and the self-management of chronic back pain.

2.4 Methods

2.4.1 Search strategy

Thorough and comprehensive searches of five electronic databases were conducted from the year 1980 when self-management emerged as a priority for health science researchers to the present (Rashiq et al., 2008). The five databases searched were:

- The Cochrane Library (2005-present) (Available year starts from 2005)
This is a suite of databases which provides reliable evidence about the effects of health care interventions, including Cochrane reviews, clinical trials, methods studies, economic evaluations and Cochrane groups.
- CINAHL (via EBSCO, 1980-present)
This covers nursing and allied health journals. It is useful for searching journal articles, books, dissertations and conference proceedings.
- Medline (via Ovid, 1980-present)
This is a specific database mainly used for searching journals covering biomedicine, medicine, nursing, dentistry, allied health and pre-clinical sciences. It also includes a small number of newspapers, magazines and newsletters.
- EMBASE (via Ovid, 1980-present)
This is used for searching journal articles in biomedicine and pharmacology. It is especially powerful in its coverage of drug and pharmaceutical research.
- PsycINFO (via Ovid, 1980-present)

This database includes journal articles, books, dissertations and theses in core psychology disciplines, behavioural sciences and mental health.

A range of keywords and subject headings representing patient-professional partnerships, and self-management of chronic back pain were used to maximise the retrieval of relevant studies (see Appendix i). Government reports and publications were read. Reference lists and citation indexes of relevant articles were scrutinised, searching for titles which met the inclusion criteria.

2.4.2 Inclusion criteria

Any studies which reported as having undertaken primary research using any method in the following subjects were included:

- Patients were supported by having a partnership with health professionals to experience self-management of chronic back pain;
- Patients were actively involved with health professionals in developing treatment or care plans for self-managing chronic back pain;
- The influence of patient-professional partnerships on self-management of chronic back pain was reported.

2.4.3 Exclusion criteria

- Studies reporting views of the general public;
- Patients were undergoing cancer treatments or related therapies;
- Letters of opinion to peer reviewed journals;
- Editorials or commentaries;
- Non-English language studies.

2.4.4 Study selection

Records identified from the electronic searches, government publications and websites, and reference lists were imported into Endnote X6 (Reuters, 2011) to avoid duplication in the screening process (Moher et al., 2009). At the screening stage, abstracts were retrieved if the title included a reference to patient-professional partnerships and to self-management of chronic back pain. If it was not clear from the title or the abstract, the full text was retrieved and read against the inclusion criteria. Studies were excluded if they were clearly not full reports of their research, for example, conference abstracts, editorials or commentaries or news reports. Titles and abstracts were screened by the author and checked by her two supervisors. The included studies were also checked against the inclusion criteria by the two supervisors independently. Whenever a disagreement occurred, discussion continued until consensus was reached. A total of 738 studies were screened, producing 10 for inclusion, all of which used qualitative research methods. Therefore only qualitative appraisal and synthesis methods are considered in this review.

2.4.5 Data extraction

Data were extracted from the original studies into a table to present the characteristics of the studies included. Data included authors' names and the year when the study was published, country where the study was conducted, study design and aim, recruitment sample, health condition that the study focused on, method of data collection and analysis and main findings and recommendations. Data extraction was completed by the author and checked by both supervisors independently. When there was a question about the data extracted from studies, discussion continued until consensus was reached.

2.4.6 Appraisal of studies

All studies were appraised using the Critical Appraisal Skills Programme (CASP) checklist for appraising qualitative research (CASP, 2013). It consists of 10 questions that are designed to help researchers appraise qualitative studies systematically. It is easy to use, and the answers to these 10 questions indicate the trustworthiness, results and relevance of included studies. The answer “Yes”, “No” and “Cannot tell” were selected for each paper to indicate whether the CASP question had been extensively addressed, not been addressed or been addressed partially. It was decided not to exclude studies of low quality, as quality assessment in this study was used to help identify errors and flaws, rather than criticise or challenge the original studies. In addition, a study may be of low quality because although it contained valuable findings, the interpretation was weak (Dixon-Woods et al., 2004; Pawson, 2006). Previous literature also highlights that some studies provided good grounded insights into research questions, but had been written up poorly or briefly due to word length constraints so that some information had to be omitted (Seers and Toye, 2012). Appraisal of the included studies was carried out by the author and checked by the supervisors independently. Where there was a question about the identified themes, discussed continued until consensus was reached.

2.4.7 Synthesis of results

General debate continues on the appropriateness of combining qualitative studies and the methodological development of synthesising qualitative studies. For example, some have argued that the findings of individual qualitative studies were de-contextualised and those themes identified were not applicable to others (Britten et al., 2002). Various methods for synthesising qualitative studies in a systematic way are still emerging, for instance, meta-ethnography (Noblit and Hare, 1988), grounded theory synthesis (Finfgeld, 2003) and thematic synthesis (Thomas and Harden, 2008).

These approaches have been shown to be important for qualitative researchers and can deepen understanding of the contextual dimensions of health care (Walsh and Downe, 2005). The purpose of synthesising results was not to prove the methodology of data synthesis of qualitative studies, or to apply one of these approaches rigidly. Instead, it was undertaken to seek new understandings of patient-professional partnerships and patients' self-management for chronic back pain from the findings of the included qualitative studies, and then to further produce a model presenting the relationship between them.

The synthesis was guided by the principles outlined by Thomas and Harden (2008). The 10 retrieved studies were read and re-read in-depth to explore how patient-professional partnerships could influence patients self-managing their back pain. Participants' (patients and health professionals) experiences, perceptions and the original authors' findings (i.e. patient level quotes extracted from the main text, authors' interpretations and commentaries), themes and conclusions were identified and recorded. With repeated readings of the studies, these findings and themes were linked and further grouped into broader descriptive codes. These codes were then compared and contrasted across studies to generate new themes, which aimed to represent new interpretations of the findings of each included study and to further enable the development of a model illustrating the relationship between patient-professional partnerships and self-management of chronic back pain. Data synthesis was carried out by the author and checked by the supervisors independently. Where there was a question about the identified themes, discussion continued until consensus was reached.

2.5 Results

A total of 757 records were identified from the electronic search, and 62 records were identified through reference lists and government publications and websites. All references were imported into Endnote X6, to avoid duplication in the screening

process. After duplicates were removed, 738 records were available for screening. Title and abstracts were screened for the 738 records against the inclusion criteria, and 708 records were excluded. Thirty articles were retrieved in full text, and 20 of them were excluded referring to non-chronic back pain, cancer treatment, development of self-management intervention (see Figure 2.1), producing 10 studies for inclusion.

In total these 10 studies involved 223 patients and 11 health professionals, and reported a range of aspects of patient-professional partnerships and their influence on self-management of chronic back pain. Eight studies mainly reported patient-professional partnerships and their influence on self-management of chronic back pain, and two focused more on presenting patients' involvement in self-management. Of these 10 studies, only one study explored patients-professional partnerships and self-management of chronic pain from health professionals' perspectives, while the others investigated patients' experiences and beliefs of pain management. The characteristics of the 10 studies are summarised in Table 2.1.

Figure 2.1 Flow chart of study selection process

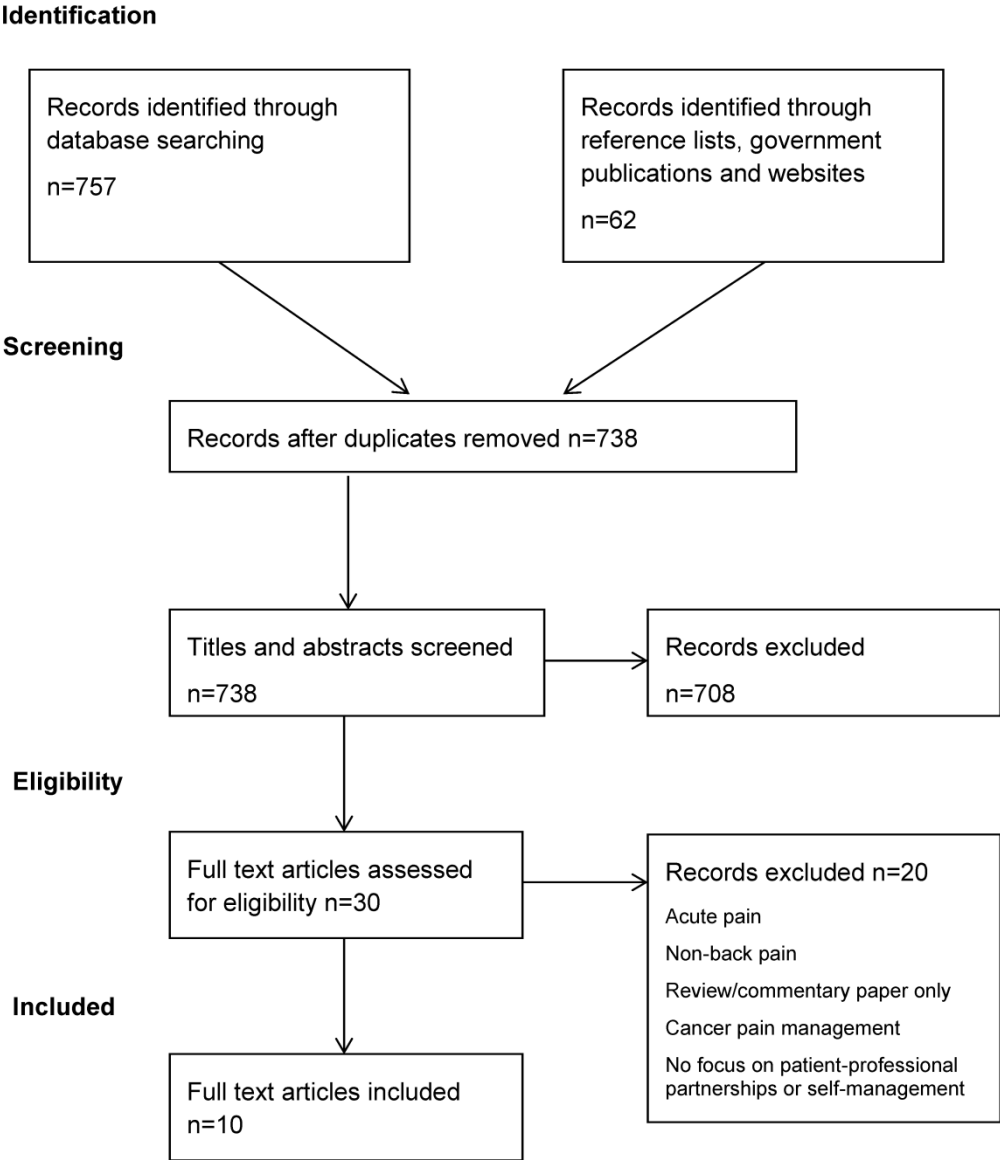


Table 2.1 Characteristics of the Included Studies

Author, year, country	Study design and aim	Recruitment and sample	Health condition	Method of data collection and analysis	Main findings	Recommendations/ implications	Quality rating
Jeffrey & Foster 2012 UK	<ul style="list-style-type: none"> • Qualitative • To understand how the personal experiences and feelings of physical therapists might influence their decision making when treating patients with non-specific low back pain 	<ul style="list-style-type: none"> • Purposive • N=11 (female=5, male=6); age range: unknown 	Persistent non-specific low back pain	<ul style="list-style-type: none"> • Semi-structured interviews • Phenomenological hermeneutics: a naïve reading, a structure analysis and a critical understanding 	<ul style="list-style-type: none"> • Three themes were produced from data analysis: physical therapists believe that non-specific low back pain has an underlying mechanical and recurring nature; their views on pain management are to involve patients to self-manage pain and functional problems; their feelings of tension between their suggested treatment for patients and patients' own beliefs and attitudes. These three themes were linked with each other • The physical therapists perceived their role was to empower patients and build their confidence to manage their pain, and they considered pain control and education as the best ways to achieve this goal • The physical therapists felt communication difficulties in 	<ul style="list-style-type: none"> • Further studies which explore patients' perceptions on lower back pain would be useful • More research on investigating approaches in which physical therapists can improve their confidence and competence in managing clinical consultation with patients would be beneficial • Increasing public knowledge of non-specific lower back pain may decrease the gap between some patients' beliefs and attitudes about best management approaches and what guidelines recommend 	Medium

Author, year, country	Study design and aim	Recruitment and sample	Health condition	Method of data collection and analysis	Main findings	Recommendations/ implications	Quality rating
					cases where their patients had conflicting beliefs and views. Therefore patients' understanding of and cooperation with these therapists' pain beliefs and treatment attitudes was seen as fundamental to building their partnerships		
Matthias et al. 2010 USA	<ul style="list-style-type: none"> • Qualitative • To examine the patient-Nurse Care Manager (NCM) relationship by focusing on patient perceptions, in order to identify how these relationships may influence patients' self-management of their pain 	<ul style="list-style-type: none"> • Purposive • N=18 (female=11, male=7); age range: unknown 	Chronic pain in the low back, hip or knee, with Brief Pain Inventory (BPI)>=5	<ul style="list-style-type: none"> • Focus groups by open-ended, semi-structured questions • Thematic content analysis techniques 	<ul style="list-style-type: none"> • Patients perceived NCM to be helpful and effective, although they were not satisfied with the treatment received in primary care • Patients were overwhelmingly positive about the self-management programme in general • Patients identified the caring and emotional support offered by the NCMs as a major benefit • Patients viewed their relationships with NCMs as central to coping with their pain 	<ul style="list-style-type: none"> • Patients' relationships with health care providers may be vital to successful management of chronic conditions • Further studies on evaluating pain self-management programmes are needed, to determine which components of these programmes provide benefits to patients • More research focusing on whether or how the relationship between patients and health providers affects 	Medium

Author, year, country	Study design and aim	Recruitment and sample	Health condition	Method of data collection and analysis	Main findings	Recommendations/ implications	Quality rating
						patients' health outcomes is needed	
Matthias et al. 2012 USA	<ul style="list-style-type: none"> Qualitative To ascertain perceptions of a multicomponent intervention tested in the Evaluation of Stepped Care for Chronic Pain (ESCAPE) trial for veterans with chronic musculoskeletal pain 	<ul style="list-style-type: none"> Purposive N=26 (female=4, male=22); age range: 22-62 (mean=40) 	Chronic musculoskeletal pain in the low back, cervical spine, or extremities (hip, knee, or shoulder)	<ul style="list-style-type: none"> Face-to-face interviews Grounded theory, codes, constant comparative methods, themes 	<ul style="list-style-type: none"> Patients valued the important role that the NCM played for them in finding ways to relieve their pain Three themes emerged related to the NCM's role in pain self-management: 1) helping patients find what works for their pain; 2) holding patients accountable for their pain management; 3) motivating and providing emotional support to patients 	<ul style="list-style-type: none"> Having an informed, empathetic health provider to help patients identify effective strategies and self-management activities, and motivation when needed is considered important by patients for successful pain self-management 	Medium
Cooper et al. 2008 UK	<ul style="list-style-type: none"> Qualitative To define patient-centredness from the patient's perspective in the context of 	<ul style="list-style-type: none"> Purposive N=25 (female=20, male=5); age range: 18-65 	Chronic low back pain	<ul style="list-style-type: none"> Semi-structured interviews Framework analysis, themes, descriptive analysis and explanatory analysis involved 	<ul style="list-style-type: none"> Six key themes (communication, individual care, decision-making, information, the physiotherapist, and organisation of care) were identified as the dimensions that the patients perceived to be important for patient-centred 	<ul style="list-style-type: none"> Physiotherapists should pay particular attention to their communication with patients Improving physiotherapists' communication skills may be beneficial 	Medium

Author, year, country	Study design and aim	Recruitment and sample	Health condition	Method of data collection and analysis	Main findings	Recommendations/ implications	Quality rating
	physiotherapy for chronic low back pain				<p>physiotherapy</p> <ul style="list-style-type: none"> • Patients considered communication to be an extremely important theme, which contributed to the other five 	<ul style="list-style-type: none"> • More research is needed to evaluate their model of patient-centred physiotherapy for chronic low back pain patients 	
Cooper et al. 2009 UK	<ul style="list-style-type: none"> • Qualitative • To explore chronic low back pain patients' perceptions of self-management following physiotherapy 	<ul style="list-style-type: none"> • Purposive • N=25 (female=20, male=5); age range: 18-65 	Chronic low back pain	<ul style="list-style-type: none"> • Semi-structured interviews • Framework analysis, themes, descriptive analysis and explanatory analysis involved 	<ul style="list-style-type: none"> • Direct access to physiotherapy and/or follow-up was desired by most patients • A few patients described that being able to telephone the physiotherapist for advice would be helpful • Exercises were identified as the most commonly used self-management strategy, as they made sense to them or fitted in with their lifestyle • Most patients felt that physiotherapy had little impact on their self-management for their low back pain 	<ul style="list-style-type: none"> • Self-management education and support may facilitate patients to self-manage their conditions • Direct access, review appointments and telephone calls should be considered for patients who self-manage their conditions 	Medium

Author, year, country	Study design and aim	Recruitment and sample	Health condition	Method of data collection and analysis	Main findings	Recommendations/ implications	Quality rating
Östlund et al. 2001 Sweden	<ul style="list-style-type: none"> • Qualitative • To explore the lay person with musculoskeletal disorders' perspective on the rehabilitation process 	<ul style="list-style-type: none"> • Purposive • N=20 (female=10, male=10); age range: 35-47 	Musculoskeletal disorders due to neck, shoulder, or low back diagnoses	<ul style="list-style-type: none"> • Semi-structured interviews • Open codes, microanalyses 	<ul style="list-style-type: none"> • Patients mainly spoke about the socio-emotional aspects of treatment they received (how and by whom), rather than the actual rehabilitation programme they had taken part in • Patients felt that finding supportive relationships in the rehabilitation process was the most important factor • Some patients described some rehabilitation programmes that were not at all fitted around their individual life situation • Most patients expressed a need for a 'professional mentor' who combines a supportive approach with individually chosen rehabilitation measures and goals 	<ul style="list-style-type: none"> • A socio-emotional rehabilitation model needs to be developed further, in order to test the socio-emotional qualities of the rehabilitation agents • Developing communication skills of rehabilitation agents is needed 	Low
Slade et al. 2009 Australia	<ul style="list-style-type: none"> • Qualitative • To determine participants' 	<ul style="list-style-type: none"> • Purposive • N=18 (female=12, 	Non-specific chronic low back pain	<ul style="list-style-type: none"> • Three focus groups using 11 pre-determined questions 	<ul style="list-style-type: none"> • Participants wanted an active role or partnership in their rehabilitation 	<ul style="list-style-type: none"> • Patients wanted a confidence-based partnership which included empathy, listening and 	Medium

Author, year, country	Study design and aim	Recruitment and sample	Health condition	Method of data collection and analysis	Main findings	Recommendations/ implications	Quality rating
	experience of exercise programmes for non-specific chronic low back pain	male=6); mean age (SD): 51.2 (9.5)		<ul style="list-style-type: none"> • Grounded theory, coded themes 	<ul style="list-style-type: none"> • Three core themes of partnership in care were identified: (1) engagement with the health care process; (2) 'listen to me: I know my own body'; (3) tell me: explain it to me so I can understand • The preference for care-seeker/care-provider partnership in management of non-specific chronic low back pain emerged as a strong theme from all the data 	<p>respect along with a comprehensive explanation of their problem and its treatment</p> <ul style="list-style-type: none"> • Clinicians may need to reflect on how they cope with the uncertainty of patients' pathology, and how this uncertainty may influence treatment decisions and communication with patients • More effective communication skills need to be developed in care-providers in order to establish equitable partnerships with patients • In practice, care-providers should pay more attention to patients' individual goals and circumstances 	
May 2001	<ul style="list-style-type: none"> • Qualitative • To produce the 	<ul style="list-style-type: none"> • Purposive • N=34 	Long histories of back pain	<ul style="list-style-type: none"> • Individual interviews by semi-structured 	<ul style="list-style-type: none"> • Five main themes describing the aspects of physiotherapy 	<ul style="list-style-type: none"> • Patients with chronic pain need personalised care, and 	High

Author, year, country	Study design and aim	Recruitment and sample	Health condition	Method of data collection and analysis	Main findings	Recommendations/ implications	Quality rating
UK	range of dimensions of care that patients perceive are important in physiotherapy	(female=20, male=14); age range: 29-77		and open-ended questions • Framework analysis, themes, coding framework, evolving themes, thematic framework	care that patients believed important were identified • Patients preferred health professionals being friendly and sympathetic and providing personalised care • Patients wanted to gain more information on their conditions and its management from health professionals • Patients hoped their treatment was a consultative, instead of a prescriptive process	someone who is skilled and knowledgeable • Patients wish to have information on their problems, advice on self-help, explanation on the treatment and be given some understanding about the prognosis of the problems • The role of therapists is vital in providing information and working with patients to address their health problems and concerns • Physiotherapists must realise the need of individualising therapy, and an active and responsive attitude in their communications with patients	
MacKichan et al. 2013	Describe patients' experience of self-care for long	• Purposive • N=23 (female=11,	Chronic back pain	• In-depth qualitative interviews • Constant	• Patients felt a responsibility to self-care • Patients' ability to self-care was	• Development of self-care in the field of healthcare may be beneficial	Medium

Author, year, country	Study design and aim	Recruitment and sample	Health condition	Method of data collection and analysis	Main findings	Recommendations/ implications	Quality rating
UK	term back pain and their views on provision of support for self-care	male=12); age range: 38-83		comparative method, coding frame, themes	various depending on their age, time, diagnosis and information • GP's support was desired by most interviewees. But a few felt that self-care support was an imposition according to their personal circumstances	• It is important to be aware of how patients respond to their health conditions and how they want to manage them • Support for managing chronic conditions should take into account patients' preferences and contexts	
May 2007 UK	<ul style="list-style-type: none"> • Qualitative • To explore patients' perspective and attitudes about back pain and its management 	<ul style="list-style-type: none"> • Purposive • N=34 (female=20, male=14); age range: 29-77 	Long histories of back pain	<ul style="list-style-type: none"> • Individual interviews by semi-structured and open-ended questions • Constant comparative analysis, themes 	<ul style="list-style-type: none"> • Six main themes (the impact of back pain on their life; perspectives about back pain; its management; their involvement in its management; what strategies they had for self-management and expectations about the episode of physiotherapy beforehand) related to patients' experiences of and attitudes about back pain and its management were identified. Two of them were patients' involvement in back pain management, and strategies for self-management 	<ul style="list-style-type: none"> • Patients with chronic pain gradually recognise the importance of their involvement in management of pain • Physiotherapists need to provide more advice, education and self-management tools to patients who desire to be involved in their treatment • Getting patients to adhere to self-management approaches may need to be constantly carried out by all 	High

Author, year, country	Study design and aim	Recruitment and sample	Health condition	Method of data collection and analysis	Main findings	Recommendations/ implications	Quality rating
					<ul style="list-style-type: none"> • Patients were learning to live with their pain, rather than expecting a cure • Many patients were interested in finding out what they could do to help manage pain themselves, and showed their positive attitude towards involvement in the treatment process 	<p>health professionals</p> <ul style="list-style-type: none"> • More research is needed to find out the characteristics of certain patients who are more likely to self-manage. Also, it would be interesting to know how patients who self-manage choose treatment and how it would differ from those do not • A definition of self-management needs to be developed, to make sure both health professionals and patients have a congruent understanding of it 	

The quality of the included studies was appraised using the CASP checklist. This checklist is not designed to provide a numerical score as a cut-off point to measure the quality of the studies. However, it is used to provide a better understanding of quality appraisal, where each study was given a summary quality rating: high, medium or low, according to the answers of the 10 questions (see Appendix ii). Studies were rated based on the criteria shown below (see Table 2.2).

Table 2.2 Quality rating criteria

Summary quality rating	Answers for 10 CASP questions
High	10 "Yes"; 1 "Cannot tell" + 9 "Yes"
Medium	2 or 3 "Cannot tell" + the rest are "Yes"; 1 "No" + 0 or 1 or 2 or 3 "Cannot tell" + the rest are "Yes"
Low	2 or more "No" + the rest are "Yes"; 4 or more "Cannot tell" + the rest are "Yes"

As a result of this, two studies were categorised as high quality, seven were medium and one was low. Studies were deemed to be of low quality mainly when there was insufficient information given to establish whether the research design was appropriate to address the research aim or to determine the justification of the research methods. Similarly, studies were designated low quality when they lacked information on the relationship between researchers and participants or in-depth description of the data analysis process.

The review and synthesis of the 10 studies generated seven themes relating to patient–professional partnerships and self-management of chronic back pain (in no particular order): effective communication, mutual understanding, roles of health professionals, information delivery, patient involvement, individualised care and healthcare service. Table 2.3 presents the appearance of the themes in each study.

Table 2.3 Comparison of themes generated by the studies

Themes	Effective communication	Mutual understanding	Roles of health professionals	Information delivery	Patient involvement	Individualised care	Health care service
Key terms	Communicate, talking, listening, face-to-face, telephone contact, language	Feeling understood, attitudes, beliefs, feelings of pain, life situation, trust	Emotional support, encouragement, motivation	Self-management strategies and skills, diagnosis, treatment	Participation, empowerment, agreement, decision-making, shared responsibility	Personalised treatment, suitable for patients	Access to physiotherapy, time, resources, follow-up contact
Jeffrey & Foster (2012)	*	*	*	*	*	*	
Matthias et al. (2010)	*	*	*	*			*
Matthias et al. (2012)	*	*	*				*
Cooper et al. (2008)	*	*	*	*	*	*	*
Cooper et al. (2009)	*	*				*	*
Östlund et al. (2001)	*	*	*			*	
Slade et al. (2009)	*	*		*	*	*	*
May (2001)	*	*	*	*	*		*
MacKichan et al. (2013)		*		*		*	*
May (2007)		*	*		*		

2.5.1 Critique of included studies

This section delivers a brief discussion of each included study, enabling the reader to have a broader understanding of the context of each study.

Study 1: Jeffrey and Foster (2012) “A Qualitative Investigation of Physical Therapists' Experiences and Feelings of Managing Patients With Nonspecific Low Back Pain”

This first study is the only study that researched the experiences of physical therapists treating and managing patients with non-specific low back pain from health professionals' perspectives, by adopting a phenomenological hermeneutic method. Eleven physical therapists who were involved in a large national survey exploring health care practitioners' pain beliefs and attitudes were purposively selected to participate in semi-structured interviews. The hermeneutic circle was used as the method of data interpretation and analysis, including a naive reading, a structural analysis, and a critical understanding. Its process was enhanced by involving a physical therapist as a researcher who was considered to have a better appreciation of the physical therapists' experiences. Finally, three linked core themes were produced, describing how physical therapists treated their patients based on their understanding of and attitudes to pain. Maintaining a strong patient-professional partnership was also a key theme for the physical therapists, who believed their role was to empower patients and support their ability to control and manage their problems. However they experienced difficulties in communicating with patients in situations where patients held conflicting pain beliefs. Therefore getting patients to understand and accept the physical therapist's belief was perceived as fundamental to building patient-professional partnerships, together with improving therapists' communication skills.

Eleven participants appeared to be a small number for a qualitative sample, but it reported that no new information was being uncovered after conducting 11 interviews.

It was worth noting that this study included a physical therapist as a researcher for data analysis. This may raise a researcher bias, as the physical therapist researcher owned his/her personal beliefs and attitudes to treatment of pain, which could have been integrated into the process of data analysis. In addition, since 11 participants were selected from a nationwide survey, they might have been the participants who were more interested in back pain treatment and had more to express, resulting in some response bias. Moreover, the three identified themes were not presented to these 11 participants for their comments or confirmation.

Study 2: Matthias et al. (2010) "Self-management support and communication from nurse care managers compared with primary care physicians: a focus group study of patients with chronic musculoskeletal pain"

This study reported the relationships between patients with chronic pain (back, hip or knee) and nurse care managers (NCMs), and with their primary care physicians (PCPs) from the patient's perspective, with the intention of further evaluating its influence on their self-management of the pain. The study sample (11 females and 7 males) was a subsample of a previous trial on Stepped Care for Affective Disorders and Musculoskeletal Pain self-management. This study adopted a focus group methodology in interviewing patients primarily about the effectiveness of the self-management strategies learnt during the trial. Four focus groups stratified by gender were conducted, with open-ended semi-structured questions being asked. This study found that most patients were dissatisfied with the pain treatment provided in primary care; however their views on pain self-management provided by their NCMs were extremely positive, largely due to a good relationship with them.

Although this study had revealed that patients perceived their relationships with NCMs as being important to managing their pain, the original aim of this focus group study was actually to find out whether or not the components of the previous trial were useful. Patients talked about their relationships and compared them with PCPs and

NCMs in terms of their support and communication skills, however there was no interview question directly relating to it. It is unclear whether the quality of these focus groups was good enough, considering the fact that interview questions were refined after the completion of each focus group. No information or justification was given on whether a pilot interview was carried out to ensure sufficient quality of the first interview. Also, a total of only 18 participants out of 123 was a limitation, given that they were asked whether they were willing to take part in this study. Therefore it is possible that these participants might be the ones who had stronger opinions than others. As a result of it, others may have hidden their personal views from the whole group. No further information was provided on the reasons for others not participating.

Study 3: Matthias et al. (2012) “An Expanded View of Self-Management: Patients’ Perceptions of Education and Support in an Intervention for Chronic Musculoskeletal Pain”

This study focused on investigating patients’ perceptions of a self-management intervention tested in the trial of Evaluation of Stepped Care for Chronic Pain. In this study, Matthias and her colleagues adopted a grounded theory methodology to explore patients’ experiences and perceptions of pain self-management strategies learnt in this trial. Participants of this study were recruited based on their pain disability or severity reduction after the intervention. Patients were identified as responders if the reduction $\geq 30\%$ (non-responders if $< 30\%$), and as non-completers if they completed $< 50\%$ of the intervention. In total, 26 patients (4 females and 22 males), including 15 responders, nine non-responders and two non-completers were interviewed while keeping interviewers blinded to patients’ status. They found that all participants with chronic pain discussed the important role of their NCMs, although their opinions were different on the self-management strategies taught in this trial. Three themes were further developed relating to NCMs’ roles in the self-management of chronic pain: 1) finding ways to relieve patients’ pain; 2) holding them accountable

for pain management; and 3) encouraging and providing emotional support (Matthias et al., 2012, p.1020). This study also found out that a working partnership between patients and NCMs was believed by patients to be linked with their self-management ability.

Although the researchers remained blinded to patients' response status during the interviews and data analysis, no information or comparisons were shown to suggest if the findings correctly mirrored their status. Moreover, this study had included the non-completers, but no reasons were provided why those patients had not completed the trial. The number of male participants was almost six times that of females. No explanation was provided nor any suggestions about how this may have influenced the study results. There was no information given on whether a pilot interview was carried out and if so, how it was done. Although this study reported that the participants were interviewed only once two months after the completion of this trial, it is still unclear how long the effect of the NCMs' support could last on their pain self-management ability. Moreover, considering the fact that the study participants selected from this trial were veterans of the military conflicts in Afghanistan and Iraq, the findings may not be applicable to the wider population of patients with chronic back pain.

Study 4: Cooper et al. (2008) "Patient-centredness in physiotherapy from the perspective of the chronic low back pain patient"

This study focused on a physiotherapy service for patients with chronic low back pain. It explored the concept of patient-centred care in the context of physiotherapy. Twenty-five (20 females and 5 males) out of 140 prospective participants provided their consent for the semi-structured individual interview. This study adopted the framework method of data analysis, concluding that communication, individual care, information sharing, the physiotherapist, decision-making and organisation of care were six key themes relating to patient-centredness (Cooper et al., 2008, p.245). Of

these six themes, communication was extensively discussed by patients who perceived it as a fundamental component of feeling centred, and would have been more effective if it met the individual's needs. For example, patients expressed that they wanted to be treated as a person rather than only a number.

Although 25 participants sounded an appropriate number for a qualitative study, there was no information on comparing their characteristics with the other 115 people. Therefore it is unknown whether these 25 participants can be transferable to the whole population. In a similar vein, the findings of this study may not be applicable to the wider population. This study reported that their interview guide was produced based on an extensive literature review; however no evidence was shown if the interview was piloted to fit the research question. During data collection, one interview was reported as not being recorded because of the background noise. Although notes were taken during that interview and transcribed immediately, no further information was provided about whether the data collected in this case was sufficient compared with the others recorded. Another limitation of this study is the fact that the interviewer was a physiotherapist, and this information was shown on the invitation letter to patients. This may somewhat influence patients' views on the process of physiotherapy when being interviewed. Moreover, these participants were recruited from those who had already been discharged from physiotherapy sessions up to 6 months previously, to ensure they had had some time to reflect on the outcomes (Cooper et al., 2008, p.245), however no exploration was provided on whether the length of the reflection time would have an impact on the patients' perceptions on patient-centredness in physiotherapy or cause recall bias. No systematic definition was finally established to achieve the aim of this study, but six themes identified as the first step of patient-centredness may assist physiotherapists to better understand patients.

Study 5: Cooper et al. (2009) "Patients' perceptions of self-management of chronic low back pain: evidence for enhancing patient education and support"

Cooper and colleagues also published another article on exploring patients' perceptions of self-management of chronic pain following discharge from physiotherapy. In this article, they used the same data collected as in the previous one, but focused on analysing different aspects of their interviews as they had questions relating to self-management. Consequently, they found out patients' needs for future access to some forms (e.g. telephone, email) of long term relationship with their physiotherapists after having been discharged, regardless of whether they were satisfied with their treatment outcomes or whether they used strategies to self-manage their pain. They also reported that most patients were concerned that physiotherapy only had a little impact on the use of self-management strategies, as most recommended exercise did not meet their personal needs or fit in with their lifestyle.

In this article, Cooper and colleagues investigated a different research problem from their first study, focusing on exploring the extent to which physiotherapy facilitated patients with chronic pain to self-manage their condition. However they used the data obtained from the first study, and then conducted a secondary data analysis. Hence it is likely for readers to doubt whether this article had sufficient data or information to achieve its research aim. Additionally, they reported that the interview topic guide used was generated from the previous literature review; however some important preliminary work, for example, topic guide development and piloting, normally done to ensure it would reveal the research problem were either not undertaken, or omitted from their study. Although this study identified the need for longer term relationships with health professionals following physiotherapy, it still did not identify when and for how long this relationship should be formed in order to provide support for self-management.

Study 6: Östlund et al. (2001) “‘It was really nice to have someone’-Lay people with musculoskeletal disorders request supportive relationships in rehabilitation’

This study adopted a grounded theory approach, originally to explore the perceptions of patients with musculoskeletal disorders on a rehabilitation process that aimed to recover patients’ work capacity. Twenty individual interviews (10 females and 10 males) were conducted between 1997 and 1998 and were analysed in this study. A theoretical sampling strategy was employed to select the participants from a previous project, based on gender, the duration of sickness absence on average in a year, and the previous interview content (Östlund et al., 2001, p.286). Participants had been divided into groups based on their sickness absence from work when they were interviewed individually. The research team found that patients talked more about the socio-emotional aspects of treatment they received, for example, how and by whom they had been treated, rather than the rehabilitation programmes they had attended. Patients also discussed their goals in the rehabilitation process, indicating the importance of the management of their life situation. Moreover, patients identified that having supportive relationships with family, employer and especially health care professionals, was the most essential aspect in the rehabilitation process.

No clear evidence or criteria were shown concerning how these 20 participants were selected from the previous project. It is also worth noticing that these patients had a record of at least 28 sick days in 1985, and had also been followed-up for 11 years since then. A recall bias therefore was highly likely to occur after such a long time unless a clear record was made for each year. This study reported that gender and the duration of sickness absence in average during a year (low, high, very high) were two criteria used when selecting participants; however no explanation was provided for the way in which patients were grouped for interviews. For example, two women with low sickness absence and two women with very high were interviewed first, followed by two women and two men who all had high sickness absence and finally

one woman and four men with very high sickness absence from work were interviewed (Östlund et al., 2001, p.286). If gender has an impact on the study results, then there was no justification as to how this impact was minimised. Furthermore, there was no interview topic guide available. During data analysis, although the research team reported a preliminary analysis on the whole group had been made after the first 13 interviews, no further variation was identified until the last interview was completed. It is unclear how the rest of interviews contributed to the data analysis as a whole. Also, no independent review of the transcripts was reported. The fact that the only interviewer had no experience in the field of musculoskeletal disorders rehabilitation could be another limitation of this study.

Study 7: Slade et al. (2009) “Listen to me, tell me”: a qualitative study of partnership in care for people with non-specific chronic low back pain’

This study investigated participants’ experience of an exercise programme for non-specific chronic low back pain. The authors applied a qualitative methodology and used the principles of Grounded theory in the data analysis. Eighteen people (12 females and 6 males) who had back pain for at least eight weeks and had completed or taken part in an exercise programme were recruited purposively. Three focus groups were conducted, and the research team found that all participants appeared to want an active role or partnership in their rehabilitation. Three core themes were identified from the research data: (1) engagement with the health care process; (2) listen to the patients; (3) explain to patients. Patients desired to receive clear information including pathology and management processes, and preferred a partnership in which their care-providers could listen and respect them. This study further discussed the importance of partnerships between patients and care-providers in the management of chronic back pain, which was also concluded as a strong theme from the research data.

Although a clear participant inclusion and exclusion criteria was stated in this study, there was no further information on participants' profiles. Moreover, these participants were recruited from those who had participated in an exercise programme, but it did not report how long they had been involved. Therefore it is unknown whether the length of their attendance would have an impact on their results. The process of data analysis was clearly described, particularly on its credibility. Three rounds of coding were employed to develop clear themes and categories. Two authors independently read transcripts several times to secure a full impression of the data obtained, and their findings were reviewed and compared for final agreement.

Study 8: May (2001) Part 2: An explorative, qualitative study into patients' satisfaction with physiotherapy”

This study described a range of issues which patients perceived important in physiotherapy care. Qualitative research methods were employed to explore patients' experience. A total of 125 invitation letters were sent out, and 34 (20 females and 14 males) participants were recruited purposively in order to conduct semi-structured interviews. Framework analysis was applied in the data analysis. A thematic framework was further created to ensure that those themes were comprehensive and inclusive. Five themes were identified: personal and professional manner, explaining and teaching, consultative process, structure and outcome. A critique paragraph discussing credibility, transferability, dependability and conformability of this qualitative study was also included. This study concluded that the key for back pain was the patients' ability to self-manage their problem, which required a good relationship between patients and physiotherapists (May, 2001, p.18).

This study was critiqued by conventional criterion (Lincoln, 1985). It justified the selection of semi-structured interviews, allowing exploration of patients' perspectives and ensuring the researcher was not tied to the topic guide simultaneously. The credibility of this study was affirmed, particularly on the theme 'outcome', by providing

both positive and negative statements from patients that reinforced each other. For transferability, given the fact that 125 invitations were sent out but only a quarter of those (34 people) agreed to participate who were solely back pain patients, so it was hard to decide how transferable the sample was. Also, the patients included were older, with more disabled and women than the general patients with back pain, therefore it is not possible to understand whether the sample was representative or how transferable these participants were.

Study 9: MacKichan et al. (2013) "GP support for self-care: the views of people experiencing long-term back pain"

In this study, MacKichan and colleagues looked at patients' experience of self-care as well as their views on self-care support for chronic back pain. They adopted a qualitative methodology in this study, using the constant comparative method. Thirty-nine people were invited for the interview, and 23 (11 females and 12 males) agreed to take part. They found that most participants felt responsible for their self-care, although their ability differed and could be influenced by other factors, such as age, work and family life and pain related knowledge and information. They also found that GP's support for self-care was desirable, however the fact was that GPs just provided their standard support rather than personalised support. A few participants expressed that self-care support for them was sometimes an imposition (MacKichan et al., 2013, p.216).

In this study, 39 participants were invited from a sampling frame out of 91 adults who were involved in a previous survey; however there was no detail as to how the research team used the sampling frame and how those participants were selected. Of these 39 patients, 16 potential participants either rejected or had no response to the invitation, and 23 were finally included. Although some information was similar for interviewees and non-interviewees, for example, gender, use of self-care and pain bothersomeness (MacKichan et al., 2013, p.213), no comparisons were made in

terms of age, their ability to self-care chronic pain or the degree of support that they had received from their GPs. This study reported that the 23 participants were older than the previous survey samples, but no explanation was provided for why older people were interested in participating in interviews. Furthermore, no information was given as to whether the qualitative interview was piloted.

Study 10: May (2007) "Patients' attitudes and beliefs about back pain and its management after physiotherapy for low back pain"

May also published another paper which aimed to explore patients' views and attitudes about chronic back pain and its management, using a qualitative methodology. This paper used the same research data generated from his previous study (May, 2001), but it focused on analysing different aspects. Six themes related to patients' perspective about back pain and its management were listed, covering patients' involvement in pain management and self-management strategies. May reported that many patients talked about learning to live with their problem and not expecting a complete cure, while a few complained about their specialists lacking of empathy and providing inappropriate service. However, patients were positive when enquiring about their involvement in the treatment process, and some perceived the act of seeking medical help as a way to gain greater pain self-management. A range of self-management strategies were also discussed by patients.

Six themes were produced from data analysis of this study, but one theme related to expectations about physiotherapy beforehand was not illustrated due to very limited responses. The data analysed in this study was collected eight years ago, it is unknown whether this data still reflects patients' views and attitudes on their back pain management. In May's previous study (May, 2001), it described that a total of 125 letters were sent out, whereas here it was reported that 126 invitations were sent. Hence it is impossible to know which one was accurate. It might be that this article had been written up poorly.

2.5.2 Themes

2.5.2.1 Effective communication

Eight of the 10 studies emphasised the importance of communication between health professionals and patients with chronic back pain (May, 2001; Östlund et al., 2001; Cooper et al., 2008; Cooper et al., 2009; Slade et al., 2009; Matthias et al., 2010; Matthias et al., 2012; Jeffrey and Foster, 2012). In particular, patients perceived it as fundamental in their partnerships with health professionals, and believed that it could contribute towards their ability for pain self-management (Cooper et al., 2008). Modes of communication discussed in the reviewed studies included face-to-face communication, written communication and telephone contact (Cooper et al., 2008; Cooper et al., 2009). Most of the patients felt positive about the face-to-face communication, as the language and non-verbal communication that health professionals used made them feel at the centre of care and involved in the process of their treatment. The feedback by written communication, however, was often negative when compared with face-to-face communication. For example, patient rarely found that reading a book (given by health professionals) which was written by someone with a similar kind of pain was helpful. This may indicate that patients would be more satisfied with communication that happened at a personal level, considering suffering from pain is such a unique feeling. Telephone contact was mainly considered as a form of follow-up and the perspectives on it were varied. Patients considered it helpful as a means of contact with their health professionals for advice on their condition and acted as a helpline. Some patients also suggested that health professionals should proactively contact patients to provide motivation and reassurance of the management of the pain. But those who preferred direct access felt that telephone contact would only be useful when it led them to visit health professionals in person (Cooper et al., 2009).

The experience of communication with patients or health professionals highlighted the role of effective listening. For example, when patients described their context, the feeling of pain and desired outcomes, effective listening appeared to be an effective approach for health professionals to collect evidence for supporting their advice on self-management strategies. For others, taking time and paying attention to listening was an attitude to present respect, so that patients could feel centred and be willing to cooperate with health professionals towards the self-management of their pain. For patients with 'passive' attitudes towards pain self-management, effective listening was sometimes the motivation and encouragement to inspire them to take an active role. In addition, taking time and paying attention to listening was a way to present mutual respect between patients and health professionals, enabling a patient-professional partnership to be established.

Improvement in health professionals' communication skills may be a direct way to facilitate a good patient-professional communication (Jeffrey and Foster, 2012). For example, accurate, understandable, free of jargon and lay language should be used by health professionals for a clear explanation to patients instead of using complicated medical terms (May, 2001; Slade et al., 2009). When a diagnosis presented rather abstract information to the public, specific approaches such as a model of the spine or one's MRI picture would be an easier way to explain to patients (Cooper et al., 2008).

2.5.2.2 Mutual understanding

All the studies stressed patients' need to be understood. This included patients seeking health professionals' understandings of their feelings of pain and life situations as well as health professionals explaining to patients about their diagnosis and helpful information on self-management skills. In addition, it also included health professionals wanting their patients to understand their rationale for providing chronic back pain treatment. Mutual understanding enabled patients and health professionals to exchange their different types of expertise and knowledge in order to reach a

common goal. Patients felt understood when they were listened to and believed, and when they were provided with options to participate, or not, in discussions and decisions about their treatment. The establishment of a mutual understanding was considered central to building partnerships with patients from health professionals' perspectives. They believed their role was to educate patients about appropriate behaviour and help strengthen their confidence in their ability to manage the pain (Jeffrey and Foster, 2012). In addition, a mutual understanding could facilitate the development and maintenance of mutual trust between patients and health professionals. Some patients experienced a great relief when they found someone who they could trust, and described that being treated with trust made their rehabilitation process easier, as they felt able to turn to the professional with questions and phone them whenever there was a problem (Östlund et al., 2001).

Where misunderstandings arose concerning the feelings of back pain and its management strategies, the partnership between patients and health professionals was affected to varying extents. Patients complained about their health professionals either under- or over- prescribing pain medication, because they felt that the nature of their pain had not been understood or assessed accurately by health professionals. For instance, 'to get pain medicine is like fighting Muhammad Ali', or in contrast, 'they [health professionals] kept wanting to push more medicines, more medicines [when not necessary]' (Matthias et al., 2010, p.30). Moreover, some patients complained that their health professionals did not take them seriously, as they had to describe their story several times to them. Patients further suggested that visiting the same professional would improve the continuity of the treatment, and enable professionals to gain a deeper understanding of them (Östlund et al., 2001). Health professionals' understandings of patients' pain and their life situations were improved during effective communication. This was confirmed by the patients, who further highlighted the importance of this communication and suggested that advanced communication

skills were desirable for collaboration within patient–professional partnerships (Slade et al., 2009). Others felt that inappropriate self-management strategies suggested by the health professionals had led to misunderstanding in the partnership (Cooper et al., 2009; MacKichan et al., 2013). Being misunderstood was also experienced by health professionals, who sometimes felt their advice on treatment conflicted with patients' views of their pain. They felt that these patients were seeking a 'magic cure' and did not understand the reality of what therapy could offer (Jeffrey and Foster, 2012).

Despite these difficulties, both patients and health professionals recognised that mutual understanding was closely linked with communication. Patients suggested taking time over explanations and effective listening by health professionals would help them gain a better understanding of their conditions and expectations. On the other hand, health professionals believed that it was important for patients to understand their pain management beliefs in order to further cooperate afterwards. In particular when working with or involving patients who held views in conflict with theirs, health professionals considered that it was necessary to try to influence these patients' attitudes and seek for common goals (Jeffrey and Foster, 2012).

2.5.2.3 Roles of health professionals

Health professionals, as an important part of patient-professional partnerships, and their roles were discussed in seven reviewed studies (May, 2001; Östlund et al., 2001; May, 2007; Cooper et al., 2008; Matthias et al., 2010; Matthias et al., 2012; Jeffrey and Foster, 2012). Early studies showed that patients may learn to communicate with health professionals about their treatment preferences, practise useful skills and strategies to control their problems, and evaluate the benefits and limitations of these skills by working in collaboration with health care professionals in some self-management programmes (Lorig et al., 1998; Lorig et al., 1999; Bair et al., 2009). Other research has reported that health professionals performed well in helping raise

self-efficacy in patients with chronic pain (Holman and Lorig, 2000; Bodenheimer et al., 2002; Fahey et al., 2008).

In this review, patients expressed that it was important for health professionals to be friendly and empathic, understandable, supportive and able to talk to and listen to patients. This made patients feel they were treated in a sympathetic and respectful way, and also increased patient satisfaction with the pain self-management programme (May, 2001; Matthias et al., 2010). Matthias and colleagues (2012) reported that all the patients positively evaluated the roles of their health professionals such as believing, listening and being empathetic. These participants also described their strong partnerships with health professionals, because of the role of the health professionals, which was perceived by patients as being important in helping them find strategies which worked for their pain, holding them accountable for pain management and encouraging and providing emotional support to patients. Their partnership was also believed by patients to be integral to their ability to manage pain. In May's study (May, 2001), patients preferred their health professionals' friendly and empathic attitude, the professional manner, and being sensitive to patients' needs. These characteristics represented a collection of skills owned by health professionals, including listening to the patients' concerns and understanding of their situation, giving information and seeking solutions for patients. Patients also commented positively on their health professionals' ability, enabling them to be relaxed and confident.

However, the role of health professionals was not always commented on positively. Some patients complained about the manner of their health professionals, and were very emotional about being treated as 'a number but not as an individual person (Cooper et al., 2008, p.247). Patients did not feel that they experienced patient-centred care during the time with their health professionals. Even though health professionals might be described as being competent, sometimes patients were not

satisfied with their treatment and how it was delivered, feeling that it was not patient-centred.

2.5.2.4 Information provided

Six studies presented findings concerning the information that patients received about their back pain and proposed treatment from health professionals (May, 2001; Cooper et al., 2008; Slade et al., 2009; Matthias et al., 2010; Jeffrey and Foster, 2012; MacKichan et al., 2013). Obtaining accurate information on patients' condition and treatment could build their confidence to work along with their health professionals as well as to better manage their back pain. Providing explanation and education, as part of the health professionals' role, were also highly desired by patients. Patients expected to receive information about pain, including diagnosis and prognosis, treatment processes, self-management strategies, patients' roles and responsibilities for caring for themselves and managing their own pain. Even though all of this information did not make the pain better, patients described it as a satisfactory feeling to understand what was wrong with their bodies.

Both patients and health professionals highlighted the importance of providing information and skills to help patients manage chronic back pain. In particular, explanations of the cause and prognosis of the pain and other functional problems were frequently identified as being useful. Health professionals also believed part of their role was to educate patients about appropriate behaviour to achieve self-management, for example, how to live with the pain and what to do to control it when it occurred. A good clear explanation was sought by both patients and health professionals by means of using lay language, drawings, charts and anatomical models and pamphlets. When a diagnosis presented rather abstract information to the public, a specific approach such as a model of the spine or their MRI picture was an easier way to convey the information to patients. Some forms of group activities organised by health professionals were also commented on by patients as being a

useful method to address their health information needs, but they reported that it was largely due to the individual physiotherapists who led the groups (Cooper et al., 2008).

2.5.2.5 Patient involvement

In the UK, patient involvement is driven at a policy level within the DH (Department of Health, 2013c). During the process of one's treatment, this provides a bridge connecting patients with health professionals. By involving patients and building up a patient-professional partnership, health professionals can understand patients' life situations, needs and expectations more specifically. Meanwhile, it enables patients to share more of the responsibility in managing their conditions.

In this review, five studies reported findings in relation to patients' involvement in the treatment process, with a focus on self-management and decision making (May, 2001; May, 2007; Cooper et al., 2008; Slade et al., 2009; Jeffrey and Foster, 2012). Most patients were positive about their experience of being involved in their treatment. Although they accepted that they had to live with it and no cure was available, they still had a strong interest in being involved with health professionals in their treatment. Among these patients, some treated their involvement as a way to learn new skills to further manage the pain themselves. For example, 'the act of looking for medical help was actually tied up with their idea of seeking greater self-management' (May, 2007, p.131). Decision-making also stood out as being linked with their involvement. Some patients were happy to agree with most decisions and follow the health professional's lead, while others preferred to make their own decisions on their treatment. Those who desired greater involvement in decision-making suggested that an individualised, communicative decision-making approach should be developed in their partnerships with health professionals. For example, "they [health professionals] didn't ask me what I thought I wanted, they just did what they assumed was physiotherapy", "I don't know what other treatments I could have got." (Cooper et al., 2008, p.248). Engagement which was perceived as encouragement to patients' involvement was discussed by

some patients (Slade et al., 2009; Jeffrey and Foster, 2012). Patients expressed the need of engagement with their health professionals, and they reported that this engagement improved if their health professionals understood patients' values, preferences and lifestyle with the intention of developing individualised exercise programmes. Considering health professionals' understanding of patients' pain may be improved mostly during effective communication with patients; patients again highlighted the importance of communication and suggested that advanced communication skills were desirable for collaboration within patient-professional partnerships (Slade et al., 2009).

2.5.2.6 Individualised care

Six of the studies emphasised patients' desire for individualised care (Östlund et al., 2001; Cooper et al., 2008; Cooper et al., 2009; Slade et al., 2009; Jeffrey and Foster, 2012; MacKichan et al., 2013). Individualised care was important for patients, and involved specific treatment for different health needs, personalised self-management strategies, regular communication, motivation and encouragement. Not only the treatment of chronic back pain, but also the way in which it was delivered by health professionals was expected to be individualised (Cooper et al., 2008; Cooper et al., 2009; Slade et al., 2009). Due to the nature of the pain, individualised care required a full and clear understanding of patients' conditions as well as circumstances. Most comments arose from the appropriateness of self-management skills taught by health professionals. Some patients reported that their exercises were not sufficient, only focusing on one aspect of their lives such as lifestyle, while others felt the type of exercises they received were too easy or hard to manage, leading to poor motivation. Furthermore, patients felt that some self-management strategies recommended by health professionals were not achievable, for example attending a gym or exercise classes, due to time and financial constraints. They had to work out their own exercise programme such as cycling or walking. This reflects the case that a standard self-

management plan might not be working for all. In the study conducted by Östlund et al. (2001), patients were seeking a 'professional mentor', referring to a health professional who has the ability to offer individual care with a supportive treatment approach.

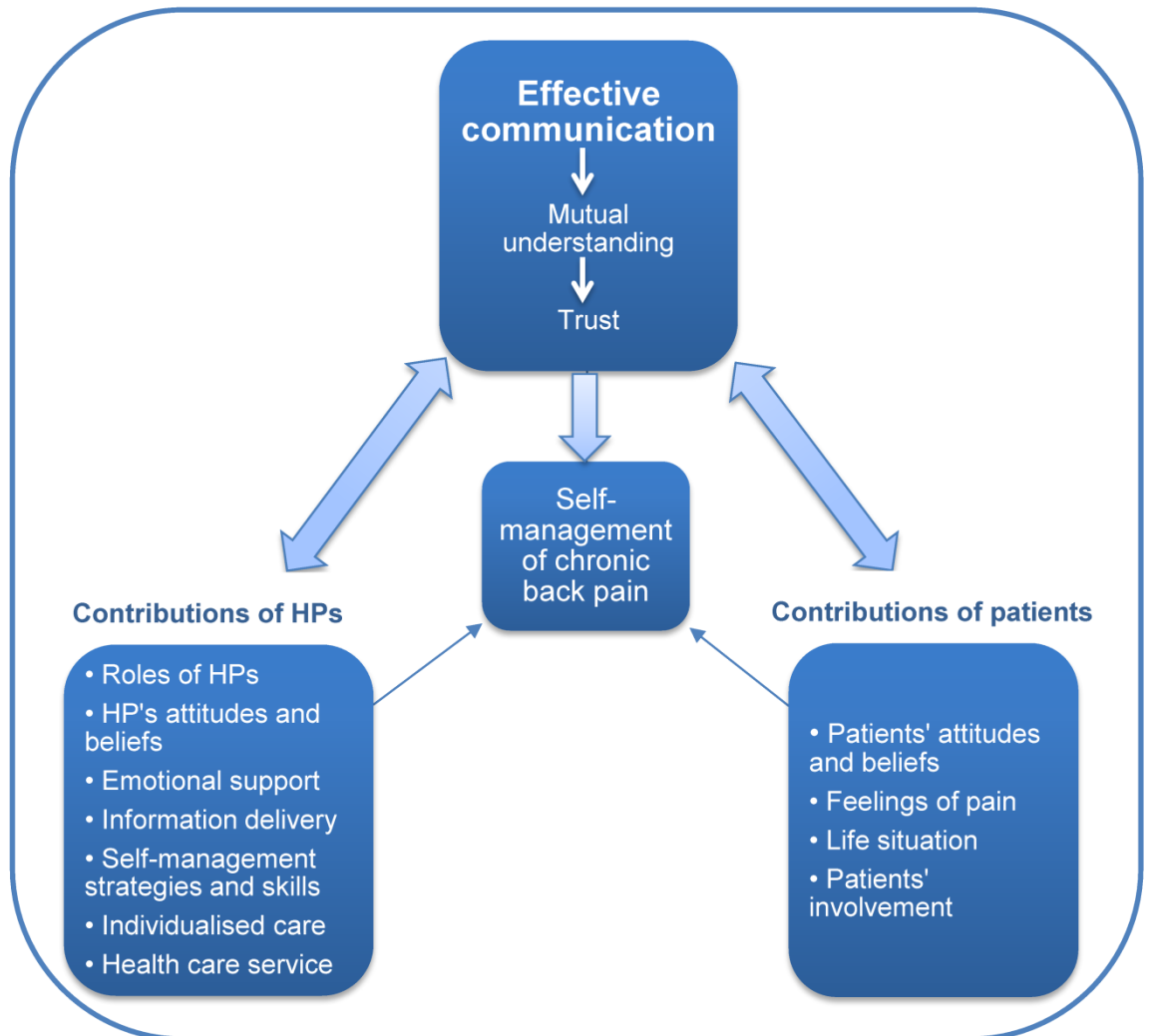
2.5.2.7 Health care service

Seven studies reported issues related to healthcare service, including its feasibility and availability (May, 2001; Cooper et al., 2008; Slade et al., 2009; Cooper et al., 2009; Matthias et al., 2010; Matthias et al., 2012; MacKichan et al., 2013). The feasibility and availability of health services were challenged by patients as a part of their perceptions of health professionals. Easy and quick access to health services, such as physiotherapy, with availability to offer follow-up contact or review sessions were desired by most patients (Cooper et al., 2008; Slade et al., 2009). However, having a large number of patients and only limited consultation time restricted the availability of health professionals' support. However, Matthias and colleagues (2012) argued that health professionals could still make patients feel important and special by focusing more on listening to and working with them towards desired outcomes, even during the short consultation process. When patients talked about whether the amount of health sessions attended was enough, it was interesting to notice that some patients were highly satisfied with the health service if a good treatment outcome had been achieved, in spite of the fact that a shorter duration of physiotherapy had been provided compared with other participants. Perhaps treatment outcomes were more valuable to patients than others factors such as the amount or the frequency of treatment (Cooper et al., 2008). Patients were also concerned about the structure of the provision of healthcare services, suggesting that they should be able to decide when to return to their health professionals (e.g. physiotherapists). However, the fact is that open access or self-referral is not always the routine pathway into pain management services in the NHS (Mallett et al., 2014).

2.6 Discussion

This review has drawn together the data from 10 qualitative studies, and explored a range of factors within patient–professional partnerships that may influence the self-management of chronic back pain. Seven themes have been generated indicating how patient-professional partnerships influence self-management. How these may assist in building patients' self-management ability is discussed below. Figure 2.2 presents a model, based on the synthesis of the results of the reviewed studies that illustrates the influence of patient-professional partnerships on the self-management of chronic back pain.

Figure 2.2 Factors within patient–professional partnerships influencing the self-management of chronic back pain (HP, health professional)



In this model, a range of identified factors within patient-professional partnerships are revealed. Effective communication is presented as a fundamental factor, helping to develop mutual understanding and trust. It performs as a connection linking the expert knowledge of health professionals with the patients' personal understandings and expertise of living with chronic back pain. In turn, effective communication serves to shape patients and health professionals' beliefs about and attitudes to chronic back pain management. Effective communication may also produce mutual understanding and trust, leading to greater cooperation between patients and health professionals.

This can provide a solid basis for patients' self-management programmes. The individual contributions of health professionals and patients are necessary components of the self-management of chronic back pain. However, the impact of their contributions will be limited without effective communication due to a lack of mutual understanding. Effective communication integrates health professionals and patients' expertise and information, facilitating the development of a partnership. Health professionals and patients may then share responsibilities and work collaboratively to address patients' health needs and achieve the self-management of chronic back pain.

Although communication has been identified as core in patient-professional partnerships, difficulties in communication still exist in reality, which may create tension between patients and health professionals. This has also been echoed in the studies reviewed (Cooper et al., 2008; Jeffrey and Foster, 2012), indicating that training to improve health professionals' communication skills as well as enhance their partnerships with patients should be targeted (Jeffrey and Foster, 2012). One purpose of effective communication is to provide explanations and educate patients. However, this needs to be a two-way communication process which enables the patient to contextualise the shared knowledge to their own reality so that they can then improve their ability to manage their pain. Effective communication is also limited by health professionals' personalities, behaviour, resources and whether or not they are willing to involve and motivate the patients in order to achieve a higher level of patient satisfaction and centredness.

Among the different types of communication discussed in this review, face-to-face communication was the most popular with the majority of patients. However, there is an inherent tension with this as presently this is the type of communication that may be least available due to the restricted availability of health professionals. Telephone contact was suggested by some patients as a way of seeking advice or follow-up,

which may suggest that some patients with chronic back pain would like some form of long term relationships with health professionals. Other resources are also available for health professionals to work with patients and to implement pain self-management in some parts of the UK. For instance, The Pain Toolkit, a selection of 12 tools, has been used in several pain clinics and administered by the health care team to guide patients in actively self-managing their back pain (The Pain Toolkit, 2013).

Some patients in this review who accepted that their pain was a long term condition with no cure expressed greater interest in being involved in the treatment process. This suggests that acceptance of the nature of chronic back pain may be the first step towards self-management and it might continuously inspire them to learn more. Patients also identified that it was important to provide personalised self-management strategies as well as the way that the service is delivered. To achieve this, it may be necessary to spend time assessing the degree of the pain they are experiencing as well as their ability to self-manage the pain in advance. Having an accurate understanding of the nature and impact of the pain is a prerequisite to designing an individualised care package as it informs the decision making process for choosing specific management strategies. This together with an understanding of patients' capability to undertake self-management strategies will help produce evidence-informed individualised care. A number of questionnaires and scales have been designed and validated for this purpose. For instance, the Partners In Health Scale, developed and validated by The Flinders University in Australia, was designed to assess patients' self-management ability for chronic conditions (The Flinders University, 2013).

Both patients and health professionals believed that one important health professionals' role was to provide education and relevant knowledge relating to self-management. However there may still be a gap between what patients expect to learn and what health professionals can provide. This finding was also supported by

previous research on pain management of older people in care homes (Schofield, 2006), in which health professionals acknowledged that they could help people manage pain by gaining further education in their use of complementary therapies. However many health professionals appear to focus more on pharmacological management without considering other options. Thus the residents with pain may never receive the information about complementary or adjuvant approaches that could be used to self-manage the pain. This suggests that it may be worth developing a systematic training programme on the self-management of chronic pain, for health professionals to be implemented in the field of pain management.

In this review, it is interesting to notice the fact that a few patients preferred to maintain their old lifestyle rather than adopting self-management strategies, even though they were supported by their health professionals (MacKichan et al., 2013). The theory of cognitive dissonance may be one possible explanation (Festinger, 1962). That is these patients understood that these self-management strategies taught by health professionals could help with relieving the pain, but did not necessarily use them. According to this theory, dissonance is uncomfortable and therefore individuals are motivated to relieve it by changing either their beliefs or their behaviour in order to re-establish an equilibrium between the two. In such instances, it is the role of the health professional to assess the individual's readiness to change, using a framework such as the Transtheoretical Model of Change (Prochaska and DiClemente, 1986). An accurate assessment of the patient's readiness to change will help inform the approach and range of interventions health professionals suggest to the patient to help them self-manage their pain. Where there is ambivalence, or motivation and self-belief is low, the use of motivational interviewing techniques may be helpful (Miller, 1983). Motivational interviewing may also be helpful in exploring and resolving ambivalence. Unlike other behavioural change interventions, it focuses on motivational processes within the patient that support changes congruent with his/her

own values and concerns, rather than being prescriptive (Miller, 1983; Rollnick et al., 2008). In many instances, self-management of chronic back pain involves exercises and correcting posture. Such exercises and physical movements could be related to the issue of safety, as few patients considered that self-management was grounded in the lay domain, or was different from conventional medical care (MacKichan et al., 2013). Financial difficulties could be another barrier to the self-management of chronic back pain. For example, patients reported that they were unable to attend the recommended exercise classes due to money constraints (Cooper et al., 2009). For health professionals, it may be useful for them to explain why some physical exercises could help control the pain, as well as providing guidance on how these exercises may be practised safely. Information on free courses run by local community leisure centres may be useful for some.

Support not only from health professionals, but also family and friends may be needed for managing patients' emotion and stress (Snelgrove and Lioffi, 2013). It may be worth involving family members in general practice consultations, to teach and explain to both patients and their families about the pain and the strategies for self-management. A biopsychosocial model is also of importance in the field of chronic pain management, which considers illness as a complex interaction of biological, psychological and social factors that influences patients' reaction to the pain (Turk and Okifuji, 2002; Gatchel et al., 2007). Self-management may also need some forms of peer support, as presented in the study conducted by Cooper et al. (2008), where patients can gain more information from others' experiences which may increase their self-efficacy (Parry and Watt-Watson, 2010). A range of peer support services for people who are living with a chronic condition have been developed. For instance, the EPP project, as discussed in the previous chapter. Peer support is often provided in a group setting facilitated by peers or health professionals. Patients tend to establish their relationships through having a similar background, health condition, religious

belief, leisure interest or age. By talking to others, patients can share experiences related to their existing health problems as well as the actions taken to manage their conditions. Previous studies have reported that peer support is an essential component in helping patients manage stress and anxiety, as patients may feel less isolated or lonely (Mental Health Foundation, 2012). However, gaining face-to-face peer support for chronic back pain could be challenging for patients whose pain has limited their physical functioning.

Some of the included studies involved patients with chronic pain in other areas of the body alongside chronic back pain. Historically, chronic pain has been recognised as a non-specific symptom of a disease process, and both practice and research often draw their attention to the treatment or care underlying the pain. However there is accumulating evidence to suggest that chronic pain can be regarded as a disease in its own right (Niv and Devor, 2004; Siddall and Cousins, 2004; Tracey and Bushnell, 2009). Regardless of the locations of chronic pain, it can have a negative impact on quality of life (QoL), including disability, depression and physical changes. These will need patients' good self-management ability to cope with on a daily basis. Therefore we included all these studies with the intention of examining patients' general pain self-management ability as a whole, rather than making suggestions on specific exercises or skills that are the most effective for patients with chronic pain in different sites.

Although having identified a number of factors in patient-professional partnerships from the included studies, there are other aspects need to be taken into consideration when exploring whether any associations exists between the nature of a partnership and a patient's ability to self-manage pain. Existing literature discussed the fact that patient's age would influence the development of partnerships with health professionals, that is, younger people are more willing to be involved in making decisions about their care (Guadagnoli and Ward, 1998). Patients' education level

may also have an impact on patient-professional relationships and patients' satisfaction. For instance, patients with lower levels of education often have higher levels of satisfaction towards their partnerships with health professionals (Anderson and Zimmerman, 1993). MacKichan et al. (2013) described that life stage transition could influence people's ability to self-care, as retired study participants had more time to attend to their back pain and could pace their activities. Research evidence has also identified that females were more confident in terms of taking care of themselves (Powell et al., 2009). Others have suggested that pain intensity, self-efficacy, QoL, mental health, corresponding treatment, performance of condition management activities, and application of the necessary skills to maintain adequate psychosocial functioning are the key factors which have potential to influence patients' ability to self-manage their chronic pain (Barlow et al., 2002; Rashed et al., 2008; De Silva, 2011). In addition, what roles the health professionals play in their partnership with patients in reality, whether their support will benefit all patients to self-manage the pain, and whether the influence of their support could last for long after patients' self-management are unknown.

2.7 Limitations of the review

Although the literature search was systematic and rigorous, there were still some barriers encountered to retrieving useful studies. The searching process was iterative and reflective to ensure the most relevant studies were included for systematic review.

Firstly, this review is limited by the fact that only studies published in English were included, which might have led to language bias (Moher et al., 1996). However, it was decided to exclude non-English studies when conducting this review, as the review team lacked expertise in translating non-English studies in English and had no funds to employ professional interpreters. Secondly, grey literature was not included which may have introduced publication bias. However, grey studies had an overall lower methodological quality and smaller effect than published literature (Egger et al., 2003;

Hopewell et al., 2007). Also, there may be some problems associated with the inclusion of grey literature, including difficulty in locating a representative sample of all unpublished studies and acquiring data from investigators (Higgins and Green, 2011). Some of the relevant studies found through the search strategy were conference abstracts, on which the full study had not been published. If certain important aspects were not included in these abstracts, they were not suitable for inclusion in the review. The five databases used in this review are the most often used key ones recommended for Healthcare. They cover the areas of nursing and allied health, biomedicine and pharmacology, medicine, dentistry and pre-clinical sciences, psychology and chemistry. Journal articles, books, dissertations and conference proceedings can be searched in these five key databases. Thirdly, the search strategy was challenged by the absence of a search subject heading clearly delineating “patient-professional partnerships”. However, key words implying the same meaning were used to minimise this limitation.

All the reviewed studies were qualitative research involving small samples ranging from 11 to 34 participants, and not all of the studies were of high quality. The findings, therefore, are not necessarily transferable. However some similar findings were reported by both low and high quality studies, which supported the decision made to not exclude studies of low quality. It may be worth for future literature review authors to consider including studies published in non-English languages, grey literature and high quality studies to overcome the above listed limitations.

2.8 Conclusion and implications for research and practice

The analysis and synthesis of findings in the 10 studies reviewed suggests the notion that a partnership between patients and health professionals may support patients to self-manage their chronic back pain. Seven themes identified within patient-professional partnerships have the potential to influence patients’ ability to self-manage their pain. Effective communication was highlighted as fundamental to the

development of mutual understanding between patients and health professionals. However it may be complex to explore the influences of patient-professional partnerships on the self-management of chronic back pain, there are still other factors, as discussed in section 2.6, which need to be taken into consideration.

Given the fact that all of the reviewed studies were happen to be qualitative, more research adopting quantitative and/or mixed methods may be needed for analysing whether any associations exist between patient-professional partnerships and patients' ability to self-manage chronic back pain. Of these 10 studies, nine explored patients' experiences of living with chronic back pain while only one examined health professionals' views on pain management. More research concerning health professionals or health service providers' perceptions would be useful.

For patients suffering from chronic back pain, accepting chronic pain itself, and seeking more information on their condition and self-management strategies to gain reassurance, may enable a better understanding of how to live with long term pain. In practice, partnership in care may be of importance between patients and health professionals, with the benefit of establishing trust and addressing patients' health needs more specifically. Health professionals need to increase their awareness of the life circumstances of patients with chronic back pain and endeavour to make their service more individualised and flexible. This may also maximise the opportunity for health professionals to involve patients, and to enable the transformation from paternalism to partnerships in health services. At the same time, emotional support needs to be given as an essential part of health professionals' role to enable genuine sympathy with and respect for patients. To healthcare organisations, the provision of self-management support in the form of self-referral or telephone consultation may usefully be considered to facilitate patients to self-manage their chronic conditions. It also would be beneficial to explore ways of guiding health professionals in developing and delivering individualised services to service users.

2.9 Research aim and objectives

From the background information and literature review of this study, it can be understood that patients are constantly highlighted as being the centre of treatment and care. Having their health problems addressed is always the priority set for both healthcare research and practice. Particularly for people with chronic back pain, developing and enhancing their ability to self-manage this condition will be beneficial and also effective for both patients and society as a whole (Gurden et al., 2012). Moreover, the research site in which this study was planned to be conducted only included a limited number of health professionals (seven members in total). It was decided that this study is to primarily focus on examining patients' perceptions. Based on the knowledge gap identified in the literature review, the research aim and objectives for this study were proposed.

The aim of this study was to explore patients' perceptions of the nature and the influence of partnerships with health professionals, on their ability to self-manage chronic back pain.

The objectives were:

1. To assess the influence of patient-professional partnerships on patients' ability to self-manage chronic back pain, and to identify any associations between them. To achieve this it will be necessary to:
 - 1) Assess patients' perceptions of their partnerships with health professionals;
 - 2) Assess patients' ability to self-manage their pain;
 - 3) Assess patients' pain status, mental health and QoL which may have an impact on their partnerships and self-management ability.
2. To explore patients' perceptions and experiences of the influence of partnerships on their ability to self-manage the pain. To achieve this it will be necessary to:

- 1) Explore patients' experience of developing partnerships with health professionals, in order to understand factors which are barriers to and/or facilitators of a good partnership;
- 2) Explore whether there are any changes in self-managing behaviour after their attendance in clinics;
- 3) Explore whether the partnerships have an influence on self-management ability:
 - If yes, explore what factors in their partnerships they think had influenced their self-management ability;
 - If no, explore reasons why they think their partnerships had not influenced self-management ability.

Chapter 3 METHODOLOGY

3.1 Introduction

Research is a process of scientific investigation, which has been defined as a systematic search for pertinent information on a specific phenomenon to test explanatory concepts and develop new theories (Kothari, 2004; Bowling, 2009). It is an academic journey of discovery to obtain new knowledge. Research in the area of health care is multidimensional; it concerns clinical research, education and social services related to health care sciences (Brink et al., 2005). It provides information on the state of health and diseases of the population, explores systematic knowledge and uses technology with the aim of improving the health status of individual groups (Bowling, 2009). This chapter presents the research methodology and specific design used as a framework for this study. In particular, it justifies the choice of a mixed methods research approach. It begins with an introduction to the different research methodologies and explains how these methodologies underpin health care research. Following this, the methodology chosen for this study is justified in detail, leading to the specific projects proposed to address the research aim.

3.2 Research methodology

Research methodology provides a systematic approach to addressing a research question as well as the philosophical foundation for conducting research. It implies more than simply the methods that are usually used to collect data. Instead, it concentrates on the concepts and theories underlying the methods and offers theoretical underpinning for understanding which method could be the most appropriate for exploring a certain phenomenon in depth. In fact, all research has a philosophical foundation. For each specific project researchers make philosophical assumptions to guide their study at a broad level. These assumptions may consist of a basic set of beliefs or a collection of available techniques (Guba and Lincoln, 2005).

A term that is often used to describe these philosophical assumptions is worldview or paradigm, referring to the shared generalisations, beliefs, concepts and values of a community of researchers (Kuhn, 1970; Creswell and Plano Clark, 2011). In this section three major methodologies in health care research are explored: quantitative, qualitative and mixed methods research. Their philosophical foundations and paradigms are presented, followed by an introduction to a number of specific research designs available within the three methodologies. The methodological approaches and methods of data collection are then examined, and their strengths and limitations are discussed.

3.2.1 Quantitative research methodology

Quantitative research has been defined in many ways. Aliaga and Gunderson (2000) once described it as a means of explaining phenomena by collecting numerical data, which are analysed using mathematically based methods, such as statistics. However, a common argument arose claiming quantitative data do not require data only in numerical form, but other types of data, such as people's experiences and attitudes, could also be transformed into quantitative form by using research instruments, for example, Likert scales (Jamieson, 2004).

Creswell (2014) redefined quantitative research as a means of "testing objective theories by examining the relationship among variables" (p.4). In the context of health and social research, one crucial part of quantitative research is the ability to measure and evaluate phenomena and relate them mathematically to other observable phenomena.

The quantitative research approach primarily follows the confirmatory scientific method, i.e., researchers state a hypothesis based on extant theory; they then collect empirical data to test the hypothesis and finally decide tentatively to either accept or reject the hypothesis on the basis of data analysis (Johnson and Christensen, 2004).

Quantitative research is often associated with a postpositivist worldview (Creswell and Plano Clark, 2011). Researchers conduct research based on their assumptions of determinism, which implies that all procedures are determined by one or more causes. Also, quantitative research normally narrows the research scope and focuses on the interrelation of selected variables (Johnson and Christensen, 2004). For example, researchers may randomly assign research participants into experimental and control groups, manipulate only one factor in the experimental group, and then examine the research results. In quantitative studies researchers attempt to study a phenomenon from a neutral standpoint and avoid human bias whenever possible, using standardised questionnaires and measuring tools to measure observed variables. Finally, statistical criteria are often used to draw many conclusions to verify and refine the theories (Slife and Williams, 1995).

3.2.1.1 Quantitative research designs

In the field of nursing and health care research quantitative approaches can be very useful for addressing questions of effectiveness. Broadly speaking, quantitative research designs are classified into two areas: observational studies and experimental studies (Seers and Critelton, 2001).

Observational studies are considered to be non-intervention studies, in which researchers observe subjects and measure variables of interest without assigning treatments to the subjects. Such study designs are particularly useful when reporting the effect size and prevalence of a health condition or for describing the features of a group of patients. Research data are frequently collected from a representative sample in observational studies, and the findings are then generalised to a target population. There are three main types of observational studies: cohort, case-control and cross-sectional designs (Jepsen et al., 2004). Cohort studies are prospective; they identify and follow a group of people over time to examine how their exposure influences their health outcome (NHS Choices, 2009). With this design researchers

can study several outcomes in one single study. However, as a long period of follow-up time is required, cohort studies can be expensive and time-consuming. Case-control studies are retrospective and are often used to identify risk factors for a medical condition (NHS Choices, 2009). In a case-control design the first step is to identify people with the condition of interest. The second step is to compare these cases with individuals that do not have the condition and then look back in time to study if there are any associations between exposure and outcome. Studies with a cross-sectional design are often called prevalence studies (Last, 2001), which describe the characteristics of a population and collect research data on exposure and outcome at one point in time, simultaneously (NHS Choices, 2009). As this design does not look at time trends, it cannot establish cause-and-effect relationships.

An **experimental research design** seeks to determine whether a specific treatment or intervention affects an outcome (Creswell, 2014). Investigators usually assign a specific treatment to one group and withhold it from another and then compare the two groups to evaluate the effectiveness of this treatment. Two main study designs are used in experimental studies: true experiments and quasi-experiments (Creswell, 2014). Studies with true experimental designs investigate the cause-and-effect relationships between predictor and outcome. To be classified as truly experimental, studies must be randomised, have control groups and manipulate of the independent variable (Sousa et al., 2007). Randomised controlled trials (RCTs), one of the typical experimental designs, provide the most rigorous evidence for the effectiveness of a given intervention (Perencevich and Lautenbach, 2011). An alternative design to RCTs is the quasi-experimental study, also known as the before-after design or pre-post design (Seers and Critelton, 2001). This type of study attempts to evaluate interventions without using a randomised control group. By this method it may be difficult to attribute causation to the intervention, but it is a feasible way of assessing

the impact of an intervention or health service when conducting RCTs is not possible (Eliopoulos et al., 2004).

3.2.2 Qualitative research methodology

The historic origin of qualitative research comes from anthropology, sociology, the humanities and evaluation (Creswell, 2014). Various definitions of qualitative research have emerged over the years. There is no absolute standard definition of qualitative research, as it covers a variety of research approaches (Coates, 2004). In general, qualitative research uses empirical materials, such as interview transcripts and written notes, that are not in the form of numbers to explore and understand the meaning of individuals' experiences of a social or human phenomenon (Guest et al., 2013; Creswell, 2014). Compared with quantitative research, qualitative research is less powerful in terms of providing cause-and-effect relationships between predictors and variables. However, it may be considered the most suitable approach in health care research in terms of researchers enquiring about patients' behaviour, feelings, experiences and personal context (Bowling, 2009). It is also of great use for informing health care practice and policy, as this type of research is able to explore service users' perspectives and then enable service providers and policy makers to understand how users think of health services (Bryman, 2012).

Qualitative research mainly follows the exploratory scientific method. Researchers start their research by making observations; this is then followed by studying of these observations to determine what is occurring. Finally, researchers draw conclusions about how these observed phenomena influence the world (Johnson and Christensen, 2004). Qualitative research is mainly used to describe and interpret human experience. Such research involves raising research questions, collecting data from people in a natural setting, analysing data inductively and making interpretations to generate new theories. Qualitative approaches are often associated with a constructivism worldview (Creswell, 2014). Different experiences construct and shape

the different perspectives and behaviour of individuals. In contrast to quantitative research, qualitative research uses a wide and deep lens to examine people's choices and studies their behaviour naturalistically and holistically. Meanwhile, qualitative researchers attempt to understand the multiple dimensions and layers of the reality of the research participants, for example, how they think, how they act and how their personal history can affect their mind and performance. Hence, it is important for researchers to put themselves into someone else's shoes in order to have an insider's perspective (Johnson and Christensen, 2004). Rather than using a measuring device as in quantitative research, qualitative researchers often collect data by conducting observations and in-depth interviews. In addition, they also write field notes recording what happens around them and other relevant insights and thoughts to help with data interpretation and theory generation.

3.2.2.1 Qualitative research designs

A large number of research designs are covered under the term qualitative research (Al-Busaidi, 2008). It is beyond the scope of this thesis to deliver a detailed account of each of those designs. However, a brief introduction of the following designs, which are important and frequently used in health care research, is presented.

Phenomenological research is a design of inquiry in which researchers describe the lived experiences of a phenomenon shared by individuals or groups (Creswell, 2014). Its strength lies in exploring the underlying structure or essence of people's experience and the meaning they give to these experiences from their personal perspectives and knowledge. To capture people's experience, interviews are often used as typical methods of data collection. In a study with phenomenology it is essential for researchers to bracket, i.e., researchers need to recognise and minimise the potential effects of any preconceptions that may influence the research process, such as the researcher's pre-existing knowledge and assumptions of the phenomenon (Tufford and Newman, 2012). During data analysis researchers are recommended to

read through all the transcripts and notes first in order to identify key statements and issues. These key findings can be further organised and summarised as a set of points that can be used to question the texts and notes written by researchers. Researchers then develop key themes from these points, enabling a textual description of the experience to be generated (Lester, 1999).

Ethnography is a design of inquiry in which researchers focus on studying the shared patterns of behaviour, languages, social arrangements and actions of a cultural group over long periods (Creswell, 2014). The core aim of this design is to provide holistic insights into people's views and actions, and also the features of the location that they inhabit. Typically, researchers gather data through observations and interviews. It is often necessary for researchers to be engaged and involved directly with the world they are studying for a long period of time. Meanwhile, a large amount of notes may be essential in recording the complex nature of the social life of the participants. Ethnography data analysis can be complicated and time consuming, and it involves explicit interpretation of the meanings and functions of people's actions in an inductive thematic manner to generate tentative explanations from their primary work. Given the fact that researchers share a relationship with participants, reflexivity is a central element of an ethnographic study report for describing researchers' thoughts and experiences. Here, reflexivity is also a useful resource for readers for measuring the potential impacts on a study (Reeves et al., 2008).

Grounded theory was developed by Glaser and Strauss in 1967 during their research on dying (Glaser and Strauss, 1967). The central aim of grounded theory is to derive a theory of an action or interaction grounded in the perceptions of the participants. Grounded theory is appropriate to use when studying experiences with the aim of providing an explanation of people's practices in health and social research (Lingard et al., 2008; Creswell, 2012). As grounded theory evolved and spread, Glaser and Strauss separated and began to produce their own grounded theory data

analysis processes (Strauss, 1987; Strauss and Corbin, 1990; Glaser, 1992). Charmaz (2006) introduced another variant: constructivist grounded theory. Compared with the Straussian and the Glaserian models of grounded theory, the Charmazian variant acknowledges sociological reality and concentrates more on constructing theory from empirical data. The core feature of grounded theory is constant comparative analysis in which data collection and analysis occurs simultaneously. This iterative process allows the integration of new and obtained data, developing a more conceptual and comprehensive explanation.

Narrative research is a strategy of inquiry from the humanities in which researchers collect information by asking participants about their life stories (Creswell, 2014). In contrast with other qualitative study designs, the narrative study also includes perceptions from researchers' lives and combines these with those of participants' life stories. Therefore, narrative inquiry is a process of collaboration, which involves mutual storytelling and life experience sharing as the study proceeds. Apart from observations and interviews, autobiographical and biographical writings are also used as a data collection tool to record people's life stories (Connelly and Clandinin, 1990).

A **case study** is a qualitative research design mainly applied when the study focuses on a contemporary phenomenon within a real life context, but with little control from the researchers (Baxter and Jack, 2008). This design is increasingly used as a valuable approach in health science research with the purpose of evaluating specific programmes and interventions. Generally, the two main approaches that guide case study methodology were proposed by Stake (1995) and Yin (2009). Both approaches can provide rich holistic and in-depth meaningful characteristics of the phenomenon for researchers. Case study uses a variety of data sources and collects data through documentation, direct observations, participant-observation, interviews and archival records (Baxter and Jack, 2008). Each source is considered to be one small piece of a big "puzzle"; therefore, it is essential to collect and analyse all the pieces to gain an

understanding of the whole picture. Case study data analysis depends on the type of methodology chosen. Stake (1995) practises categorical aggregation and direct interpretation, whereas Yin (2009) describes pattern matching, linking data to propositions, explanation building, time-series analysis, logic models and cross-case synthesis.

3.2.3 Mixed methods research methodology

Research using mixed methods has become increasingly popular in health systems (Ozawa and Pongpirul, 2013). The complexity of some research problems requires answers beyond simple numbers in a quantitative study, or words and phrases in a qualitative study. Therefore, as its name indicates mixed methodology involves the combination or integration of both quantitative and qualitative research in one study. Both forms of design and data are necessary for providing a more complete understanding of inquiries, delivering multiple forms of evidence. Several definitions of mixed research methodology have emerged over the years. However, general debate continues on how and when quantitative and qualitative methods should be mixed in research processes and what a mixed research study should be composed of. Tashakkori and Teddlie (1998, p.ix) defined mixed methods research as “the combination of qualitative and quantitative approaches in the methodology of a study”. Nine years later, Johnson et al. (2007) reviewed other definitions given by 21 highly published researchers on mixed methods, in which they expressed concern about mixed components, the scope and rationale of mixing, and the stage in which mixing occurred. Based on a composite understanding of the above aspects, they finalised the definition as follows: “mixed methods research is the type of research in which a researcher/researchers combines elements of qualitative and quantitative research approaches (e.g. use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the purpose of breadth and depth of understanding and corroboration.” (Johnson et al., 2007, p.123). In the highly cited Journal of Mixed

Methods Research, a definition of mixed methods research was announced as “research in which investigator collects and analyses data, integrates the findings, and draws inferences using both qualitative and quantitative approaches or methods in a single study or a programme of inquiry.” (Tashakkori and Creswell, 2007, p.4).

The nature of mixed methods research involves much more than its definition. This type of research has strengths, which offset the limitations or weaknesses of both quantitative and qualitative methods. It also gathers more sufficient data sources by collecting two forms of data, which may further provide an enhanced understanding of some phase of the research. Meanwhile, mixed methods research boosts the use of multiple worldviews, rather than the simple adoption of worldviews for quantitative and qualitative research. Although the worldview debate mainly focuses on whether quantitative and qualitative philosophical assumptions can be combined, pragmatism is considered to be the best philosophical foundation associated with mixed methods research (Creswell and Plano Clark, 2011). Its primary focus is on the consequences of the research and what works for whom in specific contexts (Johnson and Christensen, 2004). It is also important for researchers to use both confirmatory and exploratory methods to address the problems under study, and to capture value in both the quantitative and the qualitative views of human behaviour. Meanwhile, it also requires mixed methods researchers to have a clear sense of the subjective (individual), intersubjective (cultural, contextual) and objective (material, causal) realities, to appreciate meanings and viewpoints from inside.

3.2.3.1 Mixed methods research designs

As with either quantitative or qualitative studies, research designs are of importance in mixed methods research, because they facilitate the decisions to be made on the methods researchers must use during studies and provide the logic by which they analyse and interpret the research data (Creswell and Plano Clark, 2011). In general, mixed methods designs can be fixed or emergent. Studies with fixed designs use

quantitative and qualitative methods that are prearranged. Emergent designs are undertaken when one method is deemed to be insufficient and a second method needs to be applied to address the research inquiry (Morse and Niehaus, 2009). A wide range of classifications of mixed methods designs is available, using and focusing on different terminology and features (Greene et al., 1989; Patton, 1990; Steckler et al., 1992; Greene and Caracelli, 1997; Morgan, 1998; Tashakkori and Teddlie, 1998; Creswell, 1999; Creswell et al., 2004; Teddlie and Tashakkori, 2009; Morse and Niehaus, 2009). There are also dynamic approaches that can be designed by experienced researchers, which focus on how to design a mixed methods study, rather than selecting on of the existing typology. According to Creswell and Plano Clark (2011), the four most commonly used mixed methods designs are the convergent parallel mixed design, the explanatory sequential design, the exploratory sequential design and the embedded design.

Convergent parallel design is one in which the researcher collects quantitative and qualitative data at the same time but retains each analysis separately, and then integrates the results in the overall interpretation (Creswell, 2014). The primary purpose of this design is to obtain complementary data on the same topic but in different forms to gain the best understanding of the research inquiry. It can also be used to minimise the weaknesses of one method and to compare and contrast quantitative results with qualitative results. In this design the researcher gives equal priority to both quantitative and qualitative components, and pragmatism is recommended as a philosophical assumption (Creswell and Plano Clark, 2011). It is an efficient design, as two types of data are collected at the same time. However, it provides a challenge for researchers who need to be well trained in both quantitative and qualitative research. Meanwhile, researchers need to be aware that there are different numbers of participants recruited in two projects, and to prepare for the

possible consequences of having incompatible results from the quantitative and qualitative phases.

Explanatory sequential design is a form of design in which the researcher conducts the quantitative phase first: collection and analysis of quantitative data, which is subsequently followed by the implementation of the qualitative phase: collection and analysis of qualitative data (Creswell, 2014). In this design the quantitative phase has the priority to address the research problem, and the qualitative phase is implemented based on the quantitative results, to explain them further. Finally, the researcher needs to interpret how the qualitative results can help clarify the previous quantitative results. This design is particularly useful when the researcher intends to explain the mechanism or reasons behind quantitative data and statistical results. Undertaking two research methods, for example, using questionnaires and conducting interviews, but collecting only one type of data once makes it the most straightforward design. However, this design may be time consuming as it includes two phases. It may also be challenging to obtain an ethics approval, as the qualitative phase cannot be specified exactly until the initial phase is completed (Creswell and Plano Clark, 2011). Researchers should also decide on the sample to be selected in the qualitative phase and its corresponding criteria.

Exploratory sequential design, in contrast with explanatory design, begins qualitatively. The researcher explores the perspectives of participants and analyses the data initially. The quantitative phase is then conducted to test or generalise the initial results, according to the qualitative findings. The researcher then interprets how the quantitative results help to build on the qualitative findings. The overall intention of this design is to generalise qualitative findings to a large population. It is also appropriate to use when the researcher aims to develop relevant quantitative instruments or to identify important variables that remain unknown (Creswell, 1999; Creswell et al., 2004). The research typically begins with constructivist principles to

explore people's views in depth, and then moves to postpositivist assumptions to measure multiple variables in numbers. This research design makes the qualitative approach more acceptable to quantitative-biased researchers. Also, a new instrument or measurement could be produced during the research process. However, it requires substantial time to implement and challenges the ethics approval application. Extra effort and procedures may need to be undertaken to validate any developed quantitative instruments (Creswell and Plano Clark, 2011).

An **embedded design** starts when both quantitative and qualitative data are involved within a larger design. To better address research problems, the researcher may collect and analyse quantitative data within a qualitative design, or include a qualitative phase within a quantitative design. Each type of data supports and enhances the overall design in a certain way (Caracelli and Greene, 1997; Greene, 2007). The premise of this design is that single data recourse is inadequate for answering research questions in a predominantly quantitative or qualitative study; therefore, the second data set is needed but given less priority. It is noteworthy that the inclusion of the second data is different from but tied to the primary purpose of the study. This design is appropriate when different questions need to be answered to enhance the application of a quantitative or qualitative design. As it is used to enhance the overall study, the worldview, therefore, is applied based on the primary approach, for example, postpositivism in an experimental study or constructivism in a grounded theory. A challenge in applying this design generally occurs when the researcher must decide at which point in a study to collect the second data set and how to integrate and report the results associated with two methods (Creswell and Plano Clark, 2011).

3.3 Rationale for the choice of a mixed methods design

Given the context of quantitative, qualitative and mixed methods methodologies in health care research, it is necessary for researchers to present the rationale for their

choice of methodology, and to justify its use and how it fits into their study (Creswell and Plano Clark, 2011). Of the three main approaches, mixed methods research was chosen to underpin this study, mainly as its purpose is to collect several types of data, which can provide a more comprehensive answer to a research question than a single method. Some previously published literature discusses 16 reasons for using the mixed methods approach in research (Greene et al., 1989; Bryman, 2006); therefore, the rationale for selecting a mixed methods methodology is justified by reflecting this study on those reasons identified.

A mixed methods approach was chosen for this study in response to the complexity of the research aim and objectives. Two phases were undertaken in order to achieve the research aim sufficiently. The aim of the first phase was to assess the influence of patient-professional partnerships on patients' ability to self-manage chronic back pain and to identify any associations between them. The second phase was to explore patients' perceptions and experiences of how these partnerships influenced patients' ability to self-manage their pain. These two phases required different forms of data. To quantify the frequency of factors occurring and identify potential associations that exist between the partnerships and self-management ability, statistics and a quantitative approach were required to support and test for associations. In addition, there were existing questionnaires available that were designed and validated to assess the partnerships and self-management ability of patients with long term conditions (Powell et al., 2009; The Flinders University, 2012). Therefore, a quantitative approach was used to address the first objective of this study. Similarly, a qualitative approach was required to acquire a deep understanding of patients' perceptions and experiences, as well as to provide additional information that may help explain the initial quantitative results. The choice of a mixed methods methodology ensured its ability to address different research questions and objectives within a single study, providing more evidence than either quantitative or qualitative

research alone. This rationale has also been identified and justified by Bryman (2006) and is one of the 16 reasons provided in his critique of 232 articles for combining quantitative and qualitative research.

The rationale for using a mixed methods approach identified by Bryman (2006) also include the applications of explanation and illustration. Here “explanation” means that “one approach is employed to help explain the findings generated by the other”, while “illustration” means “the use of qualitative data to illustrate quantitative findings” (Bryman, 2006, p.106). These two reasons were applicable to this study. Based on the research questions, the quantitative phase first identified any associations between dependent and explanatory variables, but a more detailed understanding of what the statistical tests or effect sizes actually meant remained unknown. The second complementary qualitative phase could help address that unknown by collecting patients’ experiences and perceptions through in-depth interviews on their partnerships with health professionals and their experiences of self-managing chronic back pain. Interviews allow open-ended responses, which provide patients with the opportunity to elaborate on the factors and circumstances influencing them (Creswell and Plano Clark, 2011). Integrating patients’ accounts with numerical data may enable an exploration of what the quantitative results meant to patients, and how and why patient-professional partnerships influence their self-management ability. The rationale for using mixed methods was that it enabled a more complete picture by addressing the “what”, “why” and “how” of the research inquiry. Quantitative analysis facilitated the identification of factors that predict the nature of patient-professional partnerships and patients’ self-management ability, while the qualitative phase helped to explain the initial quantitative results on how and why these partnerships influenced their ability to self-manage the pain.

Another rationale for employing a mixed methods approach is utility or improving the usefulness of findings. It refers to “a suggestion or recommendation, which seems to

be prominent among articles with an applied focus, that combining the two approaches will be more useful to practitioners” (Bryman, 2006, p.106). In this study the use of mixed methods generated both numerical and textual data illustrating patient-professional partnerships and patients’ self-management ability. It was forecast that the quantitative results would inform health professionals of the factors that influenced the partnerships and patients’ self-management ability, and the qualitative findings would help them understand patients’ perceptions of the service and their self-managing behaviour. To this extent, the use of a mixed methods approach may provide health professionals with potential information for improving their service and care.

The mixed methods approach also provides strengths that offset the weaknesses of both the quantitative and qualitative research. Some methodologists argued that quantitative research is weak in terms of understanding the research context and participants’ subjective experiences, while qualitative research has difficulties in generalising findings and may be biased toward researchers’ personal interpretations (Creswell and Plano Clark, 2011). Thus, the integration of both approaches reserves the strengths of each approach, making up for each of their weaknesses. Not only does this study aim to identify factors that influence patient-professional partnerships and patients’ ability to self-manage chronic back pain, but it also aims to explore patients’ perceptions of the influence of the partnerships on self-management. In line with this, the administration of existing questionnaires in identifying associations would produce statistically (non-) significant p value, and talking to patients would provide understanding of their experiences and contextual information with which to reflect the meanings of the quantitative results.

3.4 Rationale for the choice of an explanatory sequential mixed design

A short introduction of the explanatory sequential design and the other three designs has been presented in 3.2.3.1. This section justifies the choice of the explanatory sequential design for this study.

Each of these four most commonly used designs has particular strengths and limitations, and each has a different design purpose and mixing strategy. Researchers are recommended to carefully select a design that best matches the research problem, purpose and questions (Creswell and Plano Clark, 2011). An appropriate design makes the study manageable and simple to implement.

The first objective of this study was to assess the influence of patient-professional partnerships on patients' ability to self-manage chronic back pain, and to identify any associations between them. The second objective was to explore patients' perceptions of the influence of the partnerships on their self-management ability. In response to these two research objectives, an explanatory sequential design was chosen, as it was the most appropriate approach to use to address the two research objectives in a logical sequence. This design assured the suitability of the quantitative phase for answering the 'assess influence and identify associations' questions and the suitability of the second complementary qualitative phase for exploring 'patients' perceptions'. Explanatory sequential design was chosen also because this study aims to identify variables with quantitative data, and also aims to explain the meaning of the statistical tests and significant or non-significant results so as to understand the quantitative results in more depth. This design permitted the use of qualitative interviews to explain the identified influences and associations by reflecting on patients' perceptions and experiences. Another important consideration when choosing this design was that the author had recognised a number of important variables when undertaking a literature review, and obtained access to all existing questionnaires required for measuring the outcomes. Keeping in mind these reasons,

the explanatory sequential design was best suited for this study to make it straightforward to implement.

Using mixed methods designs can be challenging, as researchers are required to have knowledge and skills to collect, analyse and interpret both quantitative and qualitative data, as well as needing extra time and resources for conducting two phases in one study (Creswell and Plano Clark, 2011). As part of PhD training the author undertook specialist courses on in-depth interviewing skills at NatCen Social Research agency in London, and training on using Nvivo software to code and analyse qualitative data at the University of Leeds. The author also undertook training on health research ethics organised by the Health Research Authority of the NHS. To enhance quantitative research skills, various training courses and workshops were undertaken for learning and improving skills on quantitative data collection and analysis.

Considering the research objectives and rationales for choosing explanatory design as presented above, the author chose explanatory design that specifically comprises a quasi-experimental and grounded theory approach for the quantitative and qualitative phases, respectively. The rationale for selecting these two specific designs is presented below.

3.4.1 Rationale for the choice of a quasi-experimental design

Quasi-experimental designs are appropriate for studies that aim to evaluate an intervention without using randomisation (Eliopoulos et al., 2004; Harris et al., 2006). Although RCTs provide the most convincing evidence for evaluating effectiveness, they are not always applicable in practice. Instead, researchers choose to use quasi-experimental designs on most occasions, taking into account ethics and other potential difficulties in randomising research participants (Shadish et al., 2002; Harris et al., 2006). For example, if the effectiveness of a specific treatment has not been

demonstrated, it would be considered unethical to allow randomisation. According to the availability of control groups and the inclusion of pretests, quasi-experimental designs can be classified into four general categories: quasi-experimental designs without control groups; quasi-experimental designs using control groups but no pretest; quasi-experimental designs using control groups and pretests; and interrupted time-series designs (Cook et al., 1979; Shadish et al., 2002).

In this present study all patients with chronic back pain received services and care in pain management clinics, and there was no control group. As a consequence, a quasi-experimental without control groups design, i.e., one-group pretest-posttest design, was used, which is also referred to as a within-participants design (Shadish et al., 2002). It is a commonly used study design that consists of a single pretest measurement of the outcome construct, an implemented intervention, and a posttest measurement of the outcome construct (Harris et al., 2006). Pretest in this design serves as the “control” of the posttest. In this study patients’ baseline data measurement from their first screening assessment was the pretest, the visits to the clinics and treatment and care received from the health professionals were considered as the intervention and patients’ follow-up (three months after) data measurement was the posttest. The pretest aimed to obtain data on the nature of what patient-professional partnerships and patients’ self-management ability before their attendance in the clinics. These data could then be compared with data obtained at the follow-up. As there were no control groups, outcome measures were designed to be completed by the same patients participating in both the pretest and posttest.

In research, one or more groups containing participants who did not receive an intervention are used as control groups, so they can be compared with one or more of the experimental groups who were exposed to the treatment. The suitable control group for this present study would have been patients who were on the waiting list to attend a pain clinic or who were under the usual care from GPs over a period of three

months without having attended a pain clinic. However, including this group was considered inappropriate due to the nature of the pain clinic service. Patients have their first screening assessment only four to six weeks after being referred by their GPs, and, therefore, there was not sufficient waiting time to compose a suitable control group. Moreover, the author had no access to the local general practice system to be able to identify and recruit patients receiving the usual care from their GPs. For these reasons, the idea of employing control groups in this study was not taken forwards, and a single group pretest-posttest design was chosen.

While the RCT is considered to be the gold standard for most clinical study, it was both inappropriate and impractical for use in this present study. Firstly, the unavailability of control groups impeded the application of an RCT design. No patients would have been available for random allocation to receive either the usual care from GPs or services from the pain clinics. Also, patients referred to the pain clinics were different in terms of their levels of pain, self-management ability and clinical characteristics, and it was also impossible for the clinics to provide a standard service for all. Moreover, an RCT was also not practical in this study because of the limited information available on the patients referred to the pain clinics, the nature of the intervention and the associations between patient-professionals partnerships and patients' self-management ability of chronic back pain. There are no studies that explore the influences of patient-professional partnerships on the self-management of chronic back pain. Therefore, a quasi-experimental pretest-posttest design was chosen.

3.4.2 Rationale for the choice of a grounded theory design

The rationales for choosing a mixed methods design, comprising an explanatory sequential design and quasi-experimental design have been presented earlier in this chapter. This section justifies the choice of grounded theory as the qualitative design in this study.

Qualitative research concentrates on understanding and interpreting individuals' behaviour and experiences of a social or human phenomenon (Creswell, 2014). Among the five most frequently used qualitative research designs (see 3.2.2.1), grounded theory was considered to be the most appropriate approach for addressing the second research objective, which was to explore patients' perceptions and experiences to understand whether and how the partnerships influenced patients' ability to self-manage pain. Grounded theory evolved from sociology, and the initial goal was to study participants' actions and to generate an explanatory theory about the researched phenomenon (Glaser and Strauss, 1967). Previous studies suggested that grounded theory was useful for understanding the experience of chronic conditions (Strauss et al., 1984; Fagerhaugh, 1973; Reif, 1975; Wiener, 1975; Charmaz, 1983). Furthermore, this design enables researchers to obtain an understanding of the process by which it is happening not just a detailed description of what is happening (Artinian, 1997; Corbin and Strauss, 2008). In addition, the literature review suggested that primary studies or theories that aimed to explain how patient-professional partnerships influenced patients' ability to self-manage chronic back pain were unavailable. Thus, grounded theory was chosen to best match the research objective as well as to develop a substantive theory.

As described earlier in this chapter, both phenomenology and grounded theory designs seek to understand participants' experiences and perspectives of reality. The author felt that it was important to differentiate between these designs to further support the choice of grounded theory for this study. The major difference lies in the goals of these two designs. The initial aim of phenomenology is to describe and explore participants' experiences, and this data can only be collected from individuals who have lived through those experiences. However, grounded theory aims to understand participants' experiences and further develop an explanatory theory, which helps to explain the phenomenon under study (Starks and Trinidad, 2007).

Purposive sampling is involved in each design but in a different way. Phenomenologists seek to recruit participants and distil common features of the lived experience, and sample sizes from 1 to 10 may suffice in obtaining the essence. Grounded theorists use theoretical sampling, where researchers aim to recruit participants with different conditions so as to examine the phenomenon under multiple scopes (Starks and Trinidad, 2007). The recruitment of participants continues until it reaches data saturation, meaning no new themes emerge from the data. Due to the absence of studies exploring the influences of patient-professional partnerships on the self-management of chronic back pain, there is no evidence to conclude what the common features are in patients' experiences of living with chronic back pain. Grounded theory was favoured, as data saturation would indicate the potential terminal point for the recruitment of participants and data collection. Furthermore, patients referred to pain clinics would have different contexts, experiences of back pain and self-management abilities, and these differences would assist in understanding which factors are the facilitators of and barriers to a good partnership and factors which factors influenced their self-management ability. For these reasons, it was logical and practical to choose a grounded theory design to underpin the qualitative phase in this study.

There are several variations of grounded theory. The question remains: which variant of grounded theory best suits this study? Before making a decision on this, it was necessary to understand each variant's principles and features. Grounded theory was initially developed and described by Glaser and Strauss in the 1960s as a means to discovering theory from primary data (Glaser and Strauss, 1967), with the goal of systematising the collection, coding and analysis of qualitative data for the purpose of generating theory (Cooney, 2010). Both of the authors were sociologists but each had different research backgrounds. Glaser was trained in quantitative research methods, whereas Strauss studied qualitative research. The difference was not widely

recognised until Strauss published guidance on the grounded theory process (Strauss, 1987; Strauss and Corbin, 1990). The difference between the Glaserian and Straussian theories starts with the treatment of literature reading. Although both acknowledge that a researcher should have knowledge in a specific area, the role of literature is perceived differently. Glaser advocated that literature reviewing should be limited to sensitise one to a wide range of possibilities. Prior understandings would bend the emerging theory from its true path (Glaser, 1978; Hickey, 1997). In contrast, Strauss (1987) recognised that both understanding from literature and the researchers' past experiences could be used to motivate theoretical sensitivity and develop hypotheses. The core of the conflict between Glaser and Strauss lies in the approach to data analysis in grounded theory. Glaser (1992) stayed with the original version and believed that grounded theory was inductive only. However, Strauss (1987) indicated that induction, deduction and verification were essential in data analysis, and further specified that deduction be followed by validation and elaboration rather than verification (Strauss and Corbin, 1998). This main conflict also differentiates the coding procedures. Glaser described two levels of coding: the creation of as many categories as possible and the integration of categories (Glaser and Strauss, 1967), while Strauss defined three levels of coding, including open, axial and selective coding (Strauss and Corbin, 1990). Another difference exists in the use and constitution of memos in data analysis. Memos connect the researcher with the primary data in Glaser's approach, recording the explored ideas that separate from coding. Memos can be part of the constant comparison analysis to help generate theory (Glaser, 1978). However, Strauss suggested that results obtained from data analysis or directions for future studies could be used as memos as well (Strauss and Corbin, 1998).

As grounded theory evolved and its debate continued, an increasing number of scholars shifted from both the Glaserian and Straussian variants to adopt and

conduct diverse studies (Charmaz, 1990; Charmaz, 2006). As a student of Glaser and Strauss, Charmaz (2006) developed another new variant of grounded theory: constructivist grounded theory. Charmaz assumed that neither theories nor data are discovered in grounded theory. Instead, she stressed that multiple realities are constructed by both the researchers and the participants. Researchers are guided to construct theories through their interaction and involvement with the research participants, their perceptions and research practices (Charmaz, 2014). The researcher's definitions of reality and lived experience shape the researcher's method of data collection and analysis, and further influence the categories that are constructed.

For this present study, constructivist grounded theory design was chosen to underpin the second part of this study. This was because, first of all, the literature review in this design is not as rigid as Glaser's. Charmaz (1990) believed that a prior theoretical perspective provides greater conceptual depth and breadth for the researcher within the discipline. As part of the author's PhD study, the undertaking of an extensive literature review was the first step and essential in order to identify research completed and any methodology issues in the area. The practice of researchers beginning their studies without prior influence gained from reviewing literature or without knowledge of any theoretical concepts is generally considered unfeasible, nor is it supported (Bazeley and Jackson, 2013). Conducting a literature review as part of this study helped the author to recognise research gaps that this study could contribute to filling in. This experience clearly allowed the author to develop the research questions and potential ethical issues for this study. More importantly, this design was chosen because of its recognition and emphasis on the local worlds and multiple realities constructed by all parties in the data analysis. From a social constructionist perspective, it is the researcher's decision to ask questions of participants and to choose methods of data analysis (Charmaz, 2014). Therefore, the

theory generation consists of the “researcher creating discoveries about the data and constructing the analysis” (Charmaz, 1990, p.1165). It is the interaction between the researcher and the researched that results in the development of theories. In line with these reasons, a personal account is provided in Chapter 1, detailing the author’s personal background and professional experiences of related aspects of this study, which may have the potential to influence parts of this study. To this extent, the use of constructivist grounded theory in this study assists in exploring and understanding patients’ perceptions, which construct their realities, but it also acknowledges the experiences of the author and how these may influence her interpretation of the patients’ stories (Charmaz, 2006; Charmaz, 2014). Furthermore, Charmaz criticises the objectivist view formed by both Glaser and Strauss (Glaser and Strauss, 1967; Glaser, 1978; Strauss and Corbin, 1990), arguing that their approaches remain separate and distant from the participants and their realities (Charmaz, 2006). Particularly in Glaser’s understanding, data are treated as being separate from the researcher and as an untouched object; the researcher should reject all possible influences to pursue the discovery of theory (Glaser, 2002). Charmaz has also suggested that Strauss’s data analysis involving deduction and verification may force the data into predetermined categories (Charmaz, 2006). In Charmaz’s point of view a theory “explicates a phenomenon, specifies concepts which categorise the relevant phenomena, explains relationships between concepts and provides a framework for making predictions” (Charmaz, 1990, p.1164). This statement also best fits the research objective to explain any associations between patient-professional partnerships and the self-management of chronic back pain. For these reasons presented above, the constructivist grounded theory approach was chosen to guide the qualitative project of this study.

3.5 Chapter summary

In this chapter quantitative, qualitative and mixed methods research methodologies are examined and compared in response to the aim of this study. A number of research designs that have the potential to address the research objectives of this study are discussed. In particular, the selection of the mixed methods approach and explanatory sequential design is justified in detail on why they best matched the aim of this study. Following this, judgements are made about the combination of the pretest-posttest design and constructivist grounded theory, and why this combination is likely to answer the research questions most successfully.

Chapter 4 METHODS

4.1 Introduction

In response to the aim and objectives of this study, which were proposed in Chapter 2, a mixed methods approach and explanatory sequential design were selected and justified in Chapter 3, leading to the two interactive phases that constitute this research study: a quantitative phase using a pretest-posttest quasi-experimental design, followed by a complementary qualitative phase using constructivist grounded theory.

This chapter presents the methods that were used within these two phases. It begins with a description of the process of obtaining ethical and research governance approvals for this study, and details the procedures that were involved in ensuring the ethical conduct of this study. The following two sections describe the methods used in conducting the quantitative and qualitative phases of this study. In each section, the recruitment of participants, sample size calculation, data collection and data analysis are explained.

4.2 Ethics and research governance approval

When entering into a research study, researchers must anticipate any ethical issues that may arise during their investigations to ensure the dignity, rights, safety and wellbeing of participants (Guillemin and Gillam, 2004). These issues apply to all stages of research, for instance, gaining local permission from each site prior to conducting the study, preparing documents by using participant-friendly language at the beginning of the study, respecting the site, ensuring transparency with participants during data collection, and respecting the privacy and anonymity of participants during data analysis. In the UK, research activity involving patients, service users, care professionals or volunteers, or their organs, tissue or data, is required to obtain ethical

approval by an independent ethics committee to ensure it meets ethical standards (Department of Health, 2005).

For this study, the ethics application was submitted to the Bradford Leeds Research Ethics Committee Centre by completing the Integrated Research Application System (IRAS) online form. The University of Leeds acted as the sponsor for this study. Other supporting documents reviewed by the committee included a study advertisement poster (Appendix iii), study protocol, a summary of the study, participant information sheets (Appendix iv), participant consent forms (Appendix v), study questionnaires (Appendix vi), interview topic guides for both researcher and participants (Appendices viii and ix), and the curriculum vitae of the research team. Pre-contact was also made with the research site – the SpineFit Service at Leeds Community Healthcare Trust, which provides pain management support and advice for adults living with long term back pain. SpineFit clinics are located in seven health centres across the city of Leeds, and the manager agreed that this study could be undertaken in three of the clinics: St George's, Meanwood and Armley Moor Health Centres, once ethical approval and a letter of access had been obtained. The Ethics Committee meeting was attended by the author and her primary supervisor (SJC). During the meeting the committee members queried the sample size, the length of time required to complete the questionnaires and the process of patient recruitment within the qualitative phase. The committee gave provisional favourable approval pending minor corrections to the participant information sheet and consent form. All recommended corrections were made and the documentation was resubmitted, following which the committee granted ethical approval (REC reference: 13/YH/0413) (Appendix x). In the next step, Research and Development (R&D) application and Site-Specific Information forms for NHS sites were submitted to seek research governance approval from the NHS for the research that would take place in the SpineFit service at Leeds Community Healthcare Trust. As part of this process, the author was issued with an Occupational

Health Check letter from the University of Leeds and an Enhanced Certificate from the Disclosure and Barring Service (DBS). Subsequently, research management and governance approval was granted (Appendix xi) and a letter of access for research was issued by Leeds Community Healthcare Trust (Appendix xii).

Throughout this study the University of Leeds Research Ethics Policy and the Data Protection Act of 1998 provided an essential framework to guide the following steps that were taken to ensure that ethical standards were reached.

4.2.1 Providing information

In order to ensure that all patients referred to the pain clinics were fully aware of the information about this study, an A4 size poster was designed and displayed on the wall in each of the clinic waiting rooms (Appendix iii). A patient information sheet was also provided to prospective participants to ensure that they were given adequate information about the research prior to their participation. This information was sent with the patient's first clinic appointment letter, which was sent by the administrator at the pain clinics. It ensured that patients had sufficient time to read and discuss this study and their participation within it with families or friends. The two phases of this study were explained in plain language on the patient information sheet. Patients were also informed of their right to withdraw from this study at any time without giving any reason, and that this would not affect the medical care they received. Patients were asked by health professionals whether they had received the information sheet on their first visit. Patients who showed an interest in taking part in this study were again asked by the author to ensure that they had read and understood the information sheet, prior to the administration of the questionnaires. The author also offered an opportunity for patients to ask questions about anything they needed clarifying in regards to this study.

4.2.2 Obtaining consent

Upon the patients' first visit to the SpineFit service, health professionals asked whether they were interested in taking part in this study. Patients who gave their verbal consent to the health professionals were then introduced to the author. After the patients had gained a full understanding of the patient information sheet and had decided to take part, consent forms were provided for them to complete and sign. As the study comprises two phases, two separate consent forms for the quantitative and qualitative phases were developed to allow patients to decide whether to participate in one or both phases. Only patients who had indicated an interest in participating in interviews on their consent forms were invited for interviews. Before signing the consent forms, the patients were reminded verbally by the author of their right to withdraw from this study at any stage.

4.2.3 Confidentiality and data protection

A core ethical consideration during this process was to keep the data collected from the participants anonymised and confidential (Corti et al., 2000). A number of key steps were taken to ensure the confidentiality of the patients and data protection. A serial number was given to each patient included in this study. All completed consent forms, questionnaires and other paper-based data were kept in a locked filing cabinet in the author's secure office in the University of Leeds. Data entered into software for quantitative and qualitative analysis were stored on a password protected online University server. Audio data collected through interviews were also downloaded on to this server after each interview and then deleted from the recorder. Only research team members had access to the data. Patients were informed that their personal identifiable data would be removed in any publications.

4.3 Research setting

This study was undertaken in SpineFit clinics at Meanwood, St George's and Armley Moor Health Centres. SpineFit has a multi-disciplinary team consisting of seven staff members from medicine, physiotherapy and nursing backgrounds. However, this service did not cover any medical interventional treatment, such as injection therapy. Health professionals often provided information and exercises plans designed for patients' specific condition and other problems, with the aim of helping patients achieve the best QoL with their back pain. The same health professionals ran this service in three different health centres on different working days.

4.4 Pretest-posttest study

As justified in Chapter 3, a one-group pretest-posttest design was used for the quantitative phase of this study. The following sections explain in detail the procedures implemented for patient recruitment, sample size, data collection and analysis. Alternative methods for sampling and data collection are also explored, and the choice of methods for this study is justified.

4.4.1 Patient recruitment

All patients referred to the three health centres between 11th April 2014 and 30th September 2014 were sent a letter of invitation and a patient information sheet together with their first appointment letter by the administrator at SpineFit. Leeds Community Healthcare Trust issued the author with a special NHS Smartcard, with chip and password, to access the electronic systems (SystemOne) to view patients' medical records. Based on the information provided on this system, patients were screened for eligibility against the inclusion and exclusion criteria (described later). Patients who met the inclusion criteria were asked verbally by the author or the health professionals on their first appointment about their willingness to take part in this study. With the patients' permission, the author attended each of their first appointments.

Following these appointments, patients who agreed to participate in this study were invited into a private consultation room by the author for baseline data collection. Patients were asked to confirm again whether they had received the information sheet, and whether they were willing to take part in the study. In addition, if requested, further information was provided about this study. Once all the information and explanations had been provided, two separate consent forms were given to the patients to sign. Patients were then able to decide in which phase/s of this study they were willing to participate. Usually, the author attended SpineFit clinic at St George's Health Centre on Tuesdays, Meanwood Health Centre on Wednesdays and Armley Moor Health Centre on Fridays for the purpose of patient recruitment and data collection, as most newly referred patients were invited for their first appointment on these days as routine practice.

4.4.1.1 Inclusion criteria

Patients were recruited for this study if they met the following criteria:

- A history of chronic back pain for at least three months;
- Had opted in to the SpineFit service;
- Had sufficient ability to read and understand English to understand questionnaires, patient information sheets and consent forms;
- Were 18 years or over, as they needed to be able to provide full consent.

4.4.1.2 Exclusion criteria

The following patients were excluded:

- Had opted out of the SpineFit service after the first consultation;
- Were under 18 years of age;
- Had malignant pain;
- Required acute medical interventions for their pain relief.

4.4.2 Sampling

Sampling is the process of selecting a portion of the population, when, as in this study, studying the whole population is not practical. The aim was to choose a subset of patients who would be representative of all the patients referred to the SpineFit service. Generally, there are two types of sampling designs in health care research: probability sampling and non-probability sampling.

Probability sampling involves random selection, which means all patients have an equal chance of being chosen for inclusion in the study. In most cases, researchers employ a probability sampling design to identify a representative sample in order to achieve generalizability (Landreneau, 2004). Findings produced from the sample may then be used to inform researchers about the entire population. Probability sampling also minimises both sampling and selection bias. Hence, this sampling design is considered to be more accurate and rigorous in quantitative research. There are a number of probability sampling designs that researchers may use in their studies, including random samples, systematic samples, stratified samples and cluster samples (Landreneau, 2004). However, patients referred to the SpineFit clinics could not be identified individually before their first appointment. Hence, a probability sampling design was not practical in this study.

Unlike probability sampling, non-probability sampling design selects individuals by non-random methods, i.e., not all individuals are given an equal chance of being selected. This type of sampling design is less likely to produce a representative sample of the whole population (Landreneau, 2004). Although probability sampling seems to be more accurate in generating a representative sample, there may be circumstances where randomisation is impossible; for instance, when the number of individuals in a population is unknown or cannot be identified before the study is conducted, or researchers have difficulties in randomly recruiting samples due to time and resource constraints. There are five commonly used non-probability sampling

designs: convenience sampling, consecutive sampling, quota sampling, purposive sampling and snowball sampling (Explorable.com, 2009).

Of all the non-probability sampling techniques, consecutive sampling is considered to be the best because it aims to include all available individuals as part of the sample (Landreneau, 2004). Selection bias in this sampling technique is also minimised as all prospective participants have a chance of being selected. Consecutive sampling was used to recruit patients for this study. The choice was made primarily because of the limited number of prospective patients. In this pretest-posttest study, only new patients were recruited for the collection of baseline data. On average, 50 new patients are referred to the three SpineFit clinics every month and are normally discharged after four to six months. Consecutive sampling, therefore, was achievable, with the aim of including all prospective patients over a three-month period. Meanwhile, selection bias was also reduced using consecutive sampling, as all patients referred to the SpineFit clinics were invited to take part in the study. Time constraints were another consideration in employing consecutive sampling. A three-month follow-up data collection point was designed for measuring the posttest study outcomes. Also, as part of a PhD study, the author had one year only to complete patient recruitment and data collection, and using probability sampling would have required more time for the recruitment of patients.

4.4.3 Sample size

Estimating a suitable sample size is a significant but challenging process of any research study. A large number of participants increase the chance of yielding more accurate results; however, excessive responses can be time consuming, expensive and unethical. Conversely, if the sample size is smaller than required, the whole study may fail to uncover a significant outcome of interest (Machin et al., 2011). When determining the appropriate sample size, it is also important to consider the

practicalities; for example, how achievable it is and how long it may take to recruit such a number of participants.

In this study patients' self-management ability was the primary outcome. The calculation and justification of the sample size was based on a difference in self-management ability scores, measured by the Partners in Health scale (PIH, range from minimum 0 to maximum 96), before and after the development of the patient-professional partnerships, for the paired *t* test. Data collected on patients' screening assessments in the pain clinic were considered as the baseline data, and data collected three months later were the follow-up data. As the baseline and follow-up data were collected from the same patients, each patient's baseline data served as their own control for the follow-up data. The difference of interest is the standardised difference, also known as the effect size or Cohen's *d* (Cohen, 1988), and is defined as follows:

$$\textit{Standardised difference} = \frac{\textit{Target difference}}{\textit{Standard deviation}}$$

Due to a lack of information on the minimum target difference for the PIH scale in the literature, the standardised difference was unknown. Based on Table 4.1, which was designed for estimating the sample sizes required to detect a series of standardised differences with the required power (Peaeson and Haetlet, 1976), as well as the practicality (50 new patients are referred to the three clinics each month), an acceptable standardised difference of 0.30 with a 90% power level was decided upon for this study.

Table 4.1 Total sample size as a function of standardised difference (5% sig., 2-tailed paired t-test)

Standardised Difference	Power Level			
	0.99 (99%)	0.95 (95%)	0.9 (90%)	0.8 (80%)
0.10	1839	1301	1053	787
0.20	461	327	265	198
0.30	206	146	119	89
0.40	117	83	68	51
0.50	75	54	44	33
0.80	31	22	18	14
1.00	20	15	13	10
1.20	15	11	9	7

The sample size for this study was then calculated using the following formula (Peason and Haetlet, 1976; Dupont and Plummer Jr, 1990).

$$N = \frac{(t_{n-1, \frac{\alpha}{2}} + t_{n-1, \beta})^2}{d^2}$$

N = total sample size; α = probability of detecting a false effect (refers to the significant level or Type I error); β = 1- α (refers to power level), d = standardised difference. In this study, $t_{n-1, \frac{\alpha}{2}}$ value = 1.96 based on significance criteria of 5%, $t_{n-1, \beta}$ value = 1.28 based on the general acceptance of power level 90%, and d value = 0.30. Therefore a sample size of 147 was calculated after accounting for a 25% dropout rate.

4.4.4 Data collection

All research data were collected from patients referred to SpineFit clinics. Being a single group pretest-posttest study, it comprised two key elements: baseline and follow-up data collections. On the patients' first visit to SpineFit, health care trainers

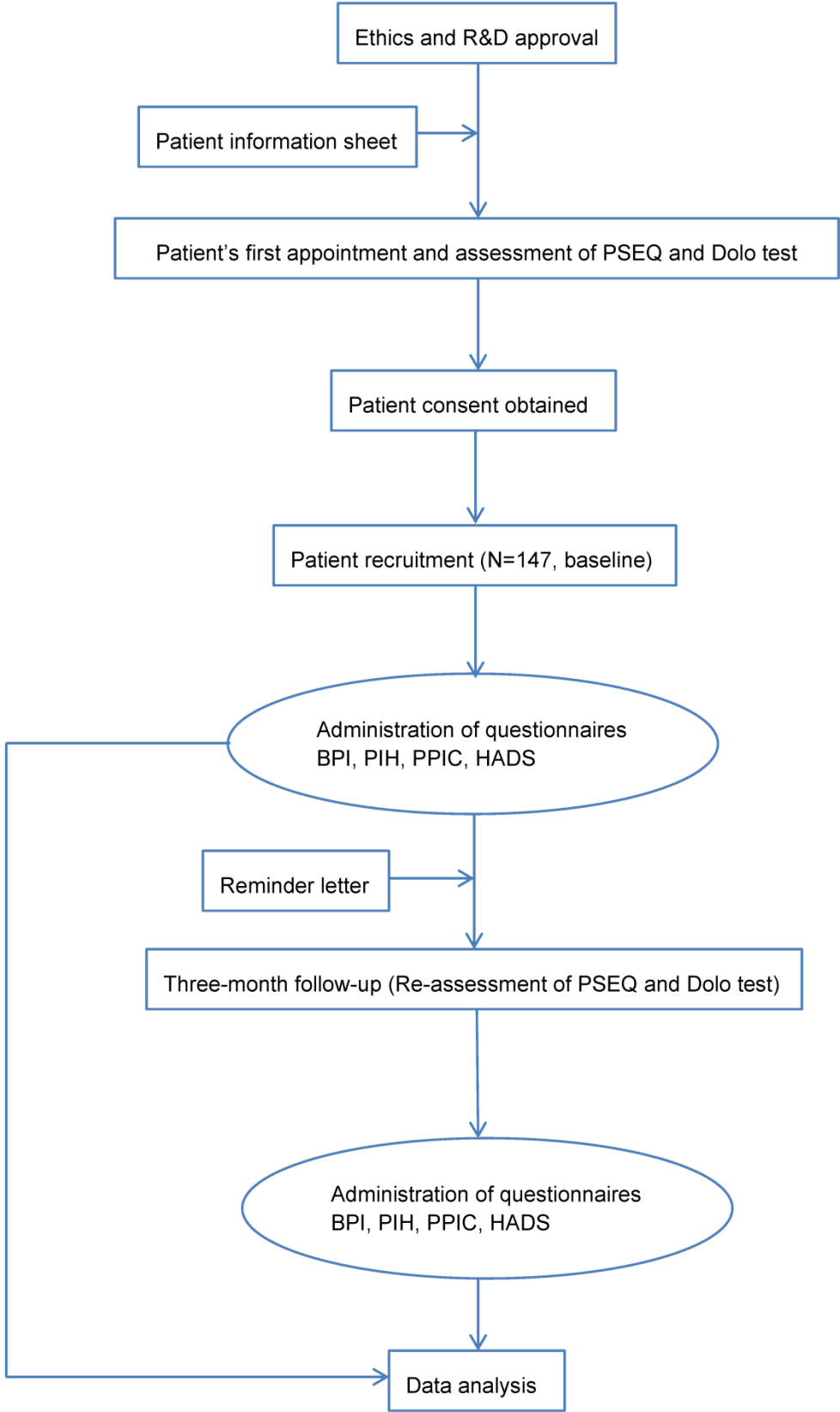
assessed their specific back pain and general health status. Patients were also asked to complete the Pain Self-Efficacy Questionnaire (PSEQ) and the DoloTest (which helps patients to describe the impact of pain on their QoL as well as their response to treatment) as routine clinical practice (the author had access to these data). After patients had completed their first appointment and agreed to participate in this study, they were invited into a private room for baseline data collection. Once patients had signed the consent forms, they were requested to fill in four validated questionnaires: the Brief Pain Inventory (BPI), the Partners in Health scale (PIH), the Patient Partnership in Care (PPiC), and the Hospital Anxiety and Depression Scale (HADS) (see Appendix vi for all the questionnaires) as part of the baseline data collection. Therefore, for the purpose of this study, patients completed four questionnaires, and the author recorded the results of the other two routinely used questionnaires. The author also collected patients' socio-demographic and clinical characteristics data from their screening questionnaires and interviews. The rationale for employing these specific outcome measures and questionnaires is explained later (4.4.5) in this chapter.

One post-test was undertaken in this study. Follow-up data were collected from the same patients three months after the first appointment. On average, patients were given four to six appointments and seen by at least two health professionals during the three months attending this service. To help maximise attendance at the follow-up data collection point, a reminder letter (see Appendix vii) about patient participation was sent two months later to the patients who had signed the consent forms. Three months after the initial assessment appointment, health professionals reassessed patients' PSEQ and DoloTest to document and monitor their treatment progress. These patients were then asked by the author to complete the same set of questionnaires once they had finished their appointments at the clinic. For each recruited patient, the date and place of both their first visit and three-month follow-up

were recorded and kept on a password protected computer in the author's secure office in the university.

Data collection for this study was completed after the patients had been reassessed by health professionals, and they had completed their follow-up questionnaires. In general, data collection for the follow-up took a longer than the time taken to collect the baseline data. A major challenge of this process was that patients could have their appointments at the same time with different health professionals in different clinics; therefore, the author was unable to reach those patients in time and had to ask them to fill in the questionnaires on their next appointment. The process of data collection is shown in Figure 4.1.

Figure 4.1 Process of quantitative data collection



4.4.5 Outcome measures

The outcome measures were selected primarily based on the research aim and objectives. The aim of the quantitative phase was to investigate the influence of patient-professional partnerships on patients' ability to self-manage chronic back pain. Patients' self-management ability of chronic back pain was the dependent variable, and the patient-professional partnership was the main explanatory variable. The literature review undertaken for this study also identified factors relating to patient-professional partnerships and self-management ability, including age, education level, pain severity, self-efficacy, mental health and QoL. These outcome domains are also supported by the work of the Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials (IMMPACT) group. The mission of the IMMPACT group is to improve the design, execution and dissemination of clinical trials on pain treatment. For these reasons, relevant questionnaires were selected to measure these outcomes based on their validity and reliability as demonstrated in previous research trials. These outcome measures are now described in detail.

4.4.5.1 Main outcome measures

4.4.5.1.1 Self-management ability

Patients' ability to self-manage chronic back pain is a core outcome following their treatment in the SpineFit clinic. Based on the definition of chronic condition self-management given by Barlow et al. (2002) (see Chapter 2), an assessment of patients' self-management should include their ability to manage symptoms, treatment, physical and psychosocial consequences and lifestyle changes. There are a number of questionnaires available for measuring people's self-management ability, such as the Pain Stages of Change Questionnaire (PSOCQ) (Kerns et al., 1997), the PIH (Battersby et al., 2003), the Health Education Impact Questionnaire (heiQ) (Osborne et al., 2007), the Self-Management Scale-30 (SMAS-30) (Schuurmans et al., 2005),

the Self-Management Scale-Short (SMAS-S) (Cramm et al., 2012), and the Diabetes Self-Management Questionnaire (DSMQ) (Schmitt et al., 2013). Although each of these questionnaires has its own advantages, limitations and reported validity and reliability, it is beyond the scope of this thesis to examine them all in detail.

As the patients referred to the SpineFit clinic suffered from different types of chronic pain, only generic measures related to pain were considered for selection. After careful consideration, PIH was chosen for this study to measure patients' ability to self-manage pain. PIH is a generic, 12-item questionnaire that covers all the areas described in Barlow et al.'s definition (Barlow et al., 2002). It measures patients' skills and abilities to self-manage chronic pain in four dimensions or themes (Petkov et al., 2010): knowledge (items 1 and 2), dealing with/managing side effects (items 9, 10 and 11), recognising and managing symptoms (items 4, 6, 7, 8 and 12) and treatment adherence (items 3 and 5). Each item is rated between 0 (very little, never, not very well) and 8 (a lot, always, very well). Each dimension score is formed as the sum of the relevant subscale scores. To reach a general index, the scores on each of the 12 questions are added together. Scores on all dimensions and the general index are linearly transformed to a common range of possible values, 0-100. A higher score suggests better self-management ability. This transformation has no effect on the tests of hypothesis. Compared with the other questionnaires, PIH is shorter and easier to answer. A good internal consistency and construct validity of PIH has been validated on patients living with a range of chronic conditions, such as diabetes, chronic pain, osteoporosis and respiratory conditions (Petkov et al., 2010).

The PIH questionnaire is the intellectual property of The Flinders ProgramTM, Flinders University, South Australia. A research license agreement was signed by the Flinders Human Behaviour & Health Research Unit and the author to ensure the legal use of the PIH in this study. Under the agreement a three-year term of use with guidelines on how to use the scale was provided by Flinders University.

4.4.5.1.2 Patient-professional partnerships

In the field of long term conditions, there are a number of practice questionnaires that can be used to measure the degree and quality of patients' partnerships with health professionals (Mathers et al., 2011). Both Long Term Condition (LCT6) and Living With Your Long Term Condition (LWYLTC) measure patients' views on their relationships with health professionals based on their experience within the last 12 months (Improvement and Efficiency, 2012; Year of Care, 2010). As only new patients referred to the clinics were recruited for this study, neither LCT6 nor LWYLTC were appropriate. Two other existing questionnaires, the Health Care Climate Questionnaire (HCCQ) and the Consultation Quality Index (CQI), measuring the partnership as a result of a recent consultation, were also carefully reviewed (Williams et al., 1996; Howie et al., 2000). Both questionnaires have demonstrated validity and reliability. However, neither of the questionnaires attempts to measure patients' confidence in managing their own health conditions as it may relate to the partnership between patients and health professionals (Powell et al., 2009).

After careful consideration of the advantages and limitations, convenience and time of completion of each questionnaire, the PPIc was selected to measure patient-professional partnerships in this study. The PPIc was designed to specifically measure the ability of health professionals to work in partnership with patients with non-specific long term conditions (Powell et al., 2009). It includes 16 items; a five-point 'poor' to 'excellent' ordinal scale is used to answer the first 11 items, and a rating scale of 0 to 10 for the rest. It also has space for patients' suggestions and comments, simple demographic questions (age range and gender) and whether they have visited the clinic. It also records the confidence of patients in managing their long term conditions in relation to the patient-professional partnership. Previous studies have shown that the PPIc is an easily completed generic instrument for patients, and it has face validity, construct validity and good internal consistency (Powell et al., 2009). In

order to achieve this level of reliability, at least 27 questionnaires should be distributed and 18 completed ones returned for further analysis (Powell et al., 2009). For this study, the index of patient-received partnerships was assessed using the first 11 scales with ordinal categories, and a total score was computed by summing subscale scores.

The Client-Focused Evaluations Programme (CFEP UK Surveys) has the copyright for PPIc. A joint agreement was signed between the Business Manager of the CFEP UK Surveys and the Research and Innovation Service, University of Leeds to ensure the author's legal use of the PPIc for this research study.

4.4.5.2 Pain-related outcomes

4.4.5.2.1 Socio-demographic and clinical characteristics

Socio-demographic data collected in this study included patients' age, gender, ethnicity, relationship status, employment status, smoking status and educational background. The author obtained these data, with the exception of educational background (this was obtained through a designed form, see below), by reviewing patients' screening questionnaires, which patients brought with them on their first appointment, and recorded them on a structured data entry form (Appendix xiii). Age was categorised into five groups: 18-30, 31-40, 41-50, 51-60, and 61 and older. Marital status compared never married with currently married/in partnership and formerly married. Respondents' economic activity was stratified into full time employed, part time employed, unemployed, retired, and others. Education attainment compared higher education with no qualifications, other qualifications, below A-level, and A-level (Appendix xiv). This form was designed by the author according to the educational classification devised by the Office for National Statistics in the UK (Harmonisation Team, 2010).

The clinical characteristics data collected included duration of pain, pain sites, medical history, previous treatment and investigations related to pain, and whether or not the patient was taking medication for pain. The author obtained patients' clinical data by reviewing their clinical notes on the NHS system, and then recorded them on the same structured data entry form. At the three-month follow-up, the number of visits to pain clinics and health professionals seen to during this period were collected by viewing patients' medical records on the electronic system (SystemOne). Two senior academics (SJC, EM) reviewed the data entry forms for accuracy, adequacy, face and content validity. The medicine management nurse (KM) in SpineFit was also consulted about the feasibility, appropriateness and practicability of the forms prior to data collection.

4.4.5.2.2 Pain severity

Pain is a subjective sensation. Instruments or tools that help measure pain severity can provide health professionals with an estimate of the severity or magnitude of pain in the most objective way possible. There is also research evidence available on the impact of pain on the development of self-management ability, which suggests that overall self-management practices are significantly poorer for patients who report their pain as severe or very severe compared with those who indicate their pain to be mild or moderate (Krein et al., 2005). Therefore, pain severity was included as a pain-related outcome in this study. Broadly, there are three widely used methods for reporting pain severity or intensity: visual analogue scales (VAS), numerical rating scales (NRS) and verbal rating scales (VRS). VAS is a unidirectional measure of pain intensity and consists of a 10-centimetre line. The scale normally begins with no pain (score 0) and ends with the worst possible pain (score 100). A higher score indicates greater pain intensity (McCormack et al., 1988). NRS is an 11-point numeric scale with 0 meaning "no pain" and 10 meaning "pain as bad as you can imagine". Respondents choose a number that best describes the severity of their pain (Cleeland

and Ryan, 1994). The VRS is usually composed of four different categories of pain: no pain, mild pain, moderate pain and severe pain. Each measure has its own advantages and disadvantages, and no single scale seems to demonstrate a persistently greater responsiveness in detecting improvement in pain compared with the others (Jensen and Karoly, 2001). However, literature has shown that VAS measures demonstrated more missing and incomplete data and are less preferred by patients (Dworkin et al., 2005). For example, for older patients or those who take opioid analgesics, the VAS measure may be more difficult to complete. Difficulties in completing the NRS have also been reported to be associated with cognitive impairment (Jensen and Karoly, 2001).

The IMMPACT group recommended an 11-point NRS measure to assess pain severity after they conducted a literature review and discussion on pain severity or intensity measures. Based on this report, an 11-point NRS, the BPI ranging from 0 being “no pain” to 10 being “pain as bad as you can imagine”, was chosen to assess patients’ pain severity. The BPI measures patients’ pain severity by asking patients to rate “worst”, “least”, “average” and “right now” pain levels (Cleeland and Ryan, 1994). The BPI user guide recommends the terms “worst” and “average” be used to represent pain severity, and a mean severity score of a combination of the four pain items be used as supplemental information (Cleeland, 2009). This was also supported by the IMMPACT recommendations for assessing pain severity in clinical trials (Dworkin et al., 2005; Dworkin et al., 2008).

Permission for the use of the BPI was sought and granted from the Department of Symptom Research, The University of Texas MD Anderson Cancer Centre.

4.4.5.2.3 Pain interference

Patients’ general activities and physical performance can be largely restricted when suffering from chronic back pain, and reductions in life and physical interference are often recognised as an indication of pain severity. However, studies have concluded

that physical functioning is not significantly associated with pain intensity (Turk, 2002). Therefore the IMMPACT group has recommended that measures of physical functioning assessing daily living activities should be included as an independent core outcome measure (Dworkin et al., 2005). Both generic and disease-specific measures are available for measuring physical functioning. However, use of a disease specific measure is only suggested when a well-established tool has been validated for the particular disease (Dworkin et al., 2005). Due to the fact that not many disease-specific measures have been designed and validated, use of generic measures, such as the Multidimensional Pain Inventory (MPI) Interference Scale (Kerns et al., 1985) or the BPI pain interference items (Cleeland and Ryan, 1994), is recommended by the IMMPACT group.

Both the MPI and BPI are valid and reliable tools for measuring pain interference with physical functioning, and have been used for different types of chronic pain in multiple settings (Dworkin et al., 2005). The MPI Interference Scale is a nine-item tool that measures the impact of chronic pain on daily activities, working ability, enjoyment of life, social activities, mood, family relationships and household tasks (Kerns et al., 1985). The BPI includes seven items relating to pain interference: general activity, mood, walking, normal work, relations with others, sleep and enjoyment of life (Cleeland and Ryan, 1994). According to the BPI user guide, pain interference is analysed by calculating a mean score of the seven interference items (Cleeland, 2009). Compared with the MPI, the BPI includes an item that specifically assesses pain interference with sleep. This is an important outcome recommended by the IMMPACT group, and, therefore, the BPI was chosen for use in this study, as using the MPI would have required the addition of another valid measure for assessing the impact of pain on sleep patterns. The BPI was also chosen because it includes items recommended for measuring pain severity. The selection of the BPI enabled the measurement of pain severity and physical functioning on one single questionnaire,

rather than using two different ones, which would have imposed an unnecessary burden on patients.

4.4.5.2.4 Mental health

Research evidence has demonstrated that chronic back pain could have a negative impact on patients' emotions, leading to stress and depression (Elizabeth Rippentrop et al., 2005; Gormsen et al., 2010; Schmidt et al., 2012). Frequently, chronic pain and depression occur simultaneously during long periods of treatment when there is poor treatment response, as well as decreased physical function and reduced QoL. Patients with chronic pain are more likely to suffer from mental health problems, particularly mood and anxiety disorders, than those not suffering from chronic pain (Demyttenaere et al., 2007). Negative emotions are also associated with lower levels of self-management skills (Das-Munshi et al., 2007; Damush et al., 2008). Therefore, a measure of patients' mental health was included as another pain-related outcome measure in this study.

Many instruments are available for assessing mental health and mental wellbeing, for instance, the Patient Health Questionnaire (PHQ-9) (Kroenke and Spitzer, 2002), the Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983), the Beck Depression Inventory (BDI) (Beck et al., 1988), the Profile of Mood States (POMS) (McNair et al., 1971) and the General Health Questionnaire (GHQ-12) (Goldberg and Williams). Of these measures, the BDI and POMS have been recommended by the IMMPACT group as core outcome measures of emotional functioning in chronic pain clinical trials (Dworkin et al., 2005).

Following a review of each of these questionnaires and discussion with the medication management nurse (KM) in the SpineFit clinic, the HADS was selected to assess patients' mental health. Compared with the BDI and the POMS, the HADS is much shorter, containing 14 statements for detecting the presence and severity of anxiety and depression in non-psychiatric settings. The HADS questionnaire comprises 14

items divided equally between the two mood states: seven questions relating to depression (HADS-D) and seven relating to anxiety (HADS-A). Each statement is scored on a four-point VRS (range 0 to 3), with 0 indicating low symptom frequencies and 3 indicating high frequencies. Previous studies have shown that the HADS has demonstrated good validity and reliability for measuring anxiety, depression and emotional distress in both hospital and community settings (Bjelland et al., 2002). According to the HADS manual, the depression and anxiety subscale were determined by adding the numbers in the Depression (D) and Anxiety (A) columns, respectively (Snaith and Zigmond, 1994). Scores indicate whether the patient is within the normal range or mildly, moderately or severely disordered in relation to the two subscales, as presented in Table 4.2.

Table 4.2 Interpretation of HADS scores (Snaith and Zigmond, 1994)

Score	Interpretation
0-7	Normal
8-10	Mild
11-14	Moderate
15-21	Severe

HADS has been used as a routine questionnaire in this pain clinic, and patients' positive feedback has included it being short and simple to complete, easy to understand and score and having a good design and layout. For these reasons, the HADS was selected to continue measuring the mental health of patients with chronic back pain in this study. A user agreement was signed with GL Assessment Company, which holds the copyright of the HADS. License fees were also paid to ensure legal use of the HADS in this study.

4.4.5.2.5 Self-efficacy

Self-efficacy refers to one's confidence to undertake the behaviour necessary to achieve a desired goal (Bandura, 1997). Previous research has shown that increasing patients' perceived self-efficacy, together with providing care and information, can

assist patients in taking control of the management of their chronic diseases (Lorig et al., 2001; Farrell et al., 2004). Other studies have also presented positive effects of improved self-efficacy on health promotion, clinical practice, patient education and health outcomes (Lorig et al., 1999; Breslow, 1999; Kerse et al., 1999; Nodturt et al., 2000; Barlow, 2013). Therefore, self-efficacy in patients with chronic back pain was measured as an outcome for predicting their confidence to self-manage pain.

Both generic measures, such as the General Self-Efficacy (GSE) (Scherbaum et al., 2006), and disease-specific measures, such as the Chronic Pain Self-Efficacy Scale (CPSS) (Anderson et al., 1995) and the PSEQ (Nicholas, 2007), have been used to assess self-efficacy. However, since the PSEQ was already being routinely used in the SpineFit pain clinic to assess patients' self-efficacy and level of pain, it was decided to continue its use in this study. Obliging patients to fill in another questionnaire to assess the same outcome would have created an unnecessary burden. Also, the use of GSE or CPSS would have disturbed routine clinical practice. The PSEQ was developed according to the concept of self-efficacy put forward by Bandura (1997), highlighting patients' confidence and experiences in accomplishing a range of activities despite the pain (Asghari and Nicholas, 2001). Compared with the GSE and the CPSS, the PSEQ is shorter. It is a self-report inventory that consists of 10 items. Health professionals at the SpineFit provided patients with access to PSEQ during their first screening assessment, and asked them to select a number on a seven-point Likert-type scale, where 0 refers to "not at all confident" and 6 refers to "completely confident". The results were then saved in patients' medical records. Scores can range from 0 to 60, with higher scores reflecting stronger self-efficacy beliefs in his or her ability to achieve all desired outcomes despite his or her pain (Nicholas, 2007; Maughan and Lewis, 2010). PSEQ has also demonstrated good validity and reliability in different studies involving patients with chronic pain (Nicholas, 1989; Asghari and Nicholas, 2001).

The PSEQ is available in the public domain at available at no cost; however, contact was still made with Professor Michael Nicholas (who originally developed PSEQ) who gave his permission to the author for its use in this study.

4.4.5.2.6 QoL

Chronic pain, and its related treatment and management, can have an overwhelming negative impact on people's QoL, and patients who live with pain may experience a much lower QoL than the general population (Fredheim et al., 2008). For example, previous studies have shown that patients with chronic pain struggle to fall or stay asleep and often experience difficulties with household chores (Breivik et al., 2006). Although the IMMPACT group has not identified QoL as a core outcome domain, a generic measure of health-related QoL, the SF-36 (Ware and Sherbourne, 1992), has been recommended for use as an indicator, to evaluate the effectiveness of chronic pain clinical trials (Dworkin et al., 2005). As it is the most widely used measure of QoL, the use of this questionnaire also permits comparisons of patient's responses to different treatments in multiple settings.

A number of instruments have been designed for the purpose of assessing people's QoL. Broadly, they can be divided into four main categories: generic measures, such as the SF-36 (Ware and Sherbourne, 1992) and Nottingham Health Profile (Hunt et al., 1981); disease-specific measures, such as the Haemo-QoL (Remor et al., 2004); dimension-specific measures, such as measures of psychological wellbeing and symptoms; and utility measures, such as the EuroQoL Scale (EQ-5D) (Rabin and Charro, 2001) and Health Utilities Index (Furlong et al., 2001).

The DoloTest (Kristiansen et al., 2010), a validated QoL assessment tool, was routinely used (every three months) during patients' treatments in the SpineFit clinics. It consists of eight VAS measuring eight domains where pain affects QoL. These include level of pain, problems with light and strenuous physical activities, problems with employment, reduced energy and social life, low spirit, and sleeping problems.

Each domain is scored ranging from 0 to 100, where 0 equals “no” and 100 equals “worst possible”. A total score is calculated by summing the scores for each of the eight items, yielding a maximum possible score of 800. Lower scores suggest better QoL (Kristiansen et al., 2010). The DoloTest has been used in several pain clinics and is proven to be a validated and reliable tool for assessing health-related QoL. The results have also shown a positive correlation with SF-36 for each domain (Kristiansen et al., 2010). In this present study, it was decided to continue using the DoloTest as an outcome measure for QoL. Inclusion of another questionnaire for the same purpose would have imposed an unnecessary burden on patients, and also would have disturbed routine practice in the pain clinics. Permission was sought from the author of the DoloTest for its legal use in this study.

4.4.6 Quantitative data analysis

In this quantitative study, data entry and data analyses were carried out using the EpiData Software (Lauritsen and Bruus, 2003) and Statistics and Data (Stata) Software version 13 (StataCorp, 2013), respectively. All the original quantitative data collected at both baseline and follow-up were first coded numerically, if they were in the form of text, and a codebook of all the created codes was prepared. For instance, for nationality, British was coded as 1 and Irish was coded as 2. These numerical codes and the original scores from each questionnaire (BPI, PIH, PPIc, HADS, PSEQ and DoloTest) were entered into the EpiData Entry Software, and then exported to Stata for further analyses. To record the number of health professionals each patient visited at the pain clinics during the three-month follow-up, data were first entered into Microsoft Excel and then also exported to Stata for further analyses.

Three socio-demographic characteristics (gender, age, and marital status), two socio-economic characteristics (education attainment and employment status), and one clinical characteristic (medication used for pain relief) were controlled for this study. The use of medication for pain relief was also controlled as a confounder, as patients

receiving self-management support for chronic pain may experience a benefit as a result of medication, rather than the practice of self-management.

4.4.6.1 Descriptive data analysis

Descriptive statistics that provide simple summaries of the observed values were used. Due to the pretest-posttest design of this quantitative phase, data collected from the same patient at baseline and three-month follow-up were paired. Both frequency and percentage were reported to illustrate the socio-demographic status and clinical characteristics of the patients, including gender, age group, ethnicity, religion, relationship status, employment status, education level and smoking status as well as pain history, pain site and other pain related features. The mean value and standard deviation (SD) were used to present the results of outcome measures. For further analysis, the paired *t* test was used to make more accurate assumptions and comparisons between baseline and follow-up data collection when data were continuous and normally distributed (Hoskin, 2012), whereas the Wilcoxon Matched-Pairs Signed-Ranks Test was used whenever the data had a non-normal distribution or were skewed (Wilcoxon, 1945).

4.4.6.1.1 Paired *t* test

Paired *t* tests were chosen to compare two quantitative measurements taken from the same individual. This type of statistical test is normally used to compare the means from two related samples, for instance, in a pretest-posttest scenario (Hsu and Lachenbruch, 2008), this then produces a single number known as a *t* value to indicate the difference. A larger *t* value represents greater difference. As it was not possible to know whether the mean value at the baseline was going to be smaller or larger than the mean at the follow-up, two-tailed tests were used. In this study, *p* value was set at 0.05 (the normal acceptable size for the Type I error) to help to decide whether or not to reject the null hypothesis.

4.4.6.1.2 Wilcoxon matched-pairs signed-ranks test

The Wilcoxon matched-pairs signed-ranks test was chosen to compare data that were non-normally distributed. It is a nonparametric version of a paired t test, and is designed to test a hypothesis about the location (median) of population distribution. In the case of comparing matched samples, it tests for a median difference of zero (Rosner et al., 2006). Similar to the paired t test, the Wilcoxon matched-pairs signed-ranks test produces a z value, and a larger z value refers to greater difference. A two-tailed test and a p value of 0.05 were also used in this test.

4.4.6.2 Regression analysis

This quantitative study was designed to identify the associations between patient-professional partnerships and patients' self-management of chronic back pain. However, conducting statistical hypothesis tests alone was not sufficient for predicting these associations, as there were other variables that could potentially affect patient's self-management of chronic back pain. In other words, a patient-professional partnership was not the only variable that could influence their self-management during the three-month follow-up. In order to estimate the relatively accurate effect of patient-professional partnerships on patients' self-management, regression analysis was conducted to study the linear relationships. Based on the nature of statistical data, for example, continuous or categorical data, and the sampling strategies, for example, random or convenience sampling, there are a large number of combinations of different types of regressions, and there is no evidence to support one particular model as being superior to another (Kleinbaum et al., 2013). As a detailed presentation of all the available regression models is beyond the scope of this thesis, this section focuses on the model that was ultimately considered for this study – hierarchical linear regression modelling.

Hierarchical linear modelling has been conducted in many research fields, including sociology, education and public health. It is a generalisation of regression methods

and is an analytical approach that allows the simultaneous investigation of the effect of group-level and individual-level variables on individual-level outcomes (Diez-Roux, 2000; Gelman, 2006). Different social contexts may have a potential impact on the participants recruited in any empirical research, leading to further interactions between the attributes of individuals. Groups are considered to be collections of independent individuals, implying that individuals may be further nested within geographical areas or organisations. Therefore, studies examining differences in outcomes of interest between individuals may need to take into account possible differences in the groups to which the individuals belong, and studies of groups may need to consider individuals' differences within the group (Diez-Roux, 2000). Hierarchical linear modelling was chosen because the data collected from patients had a hierarchical structure, and this approach recognises the existence of such data hierarchies. It has been suggested that data collected at different times and under different conditions are nested within each study participant in repeated measures research (Raudenbush and Bryk, 2002). Therefore, in this study the individual patient responses with repeated measures (level 1) nested within patients (level 2), allows for the control of unmeasured confounders and the presumption that the coefficients are constant over time. Meanwhile, patients' self-management ability in the same health centre was likely to be clustered due to the influence of unmeasured geographic and health centre characteristics, for instance, population density and centre size. A hierarchical regression model with a three-level nested structure was used in this study, to allow for these health centre effects on self-management, in which measuring time at level 1 was grouped within patient at level 2 which was then grouped within health centre at level 3. A discrete measure was used for time (0=baseline, 1=three months). A lack of consideration of any level may result in underestimated standard errors of regression coefficients and inefficient estimates (Diggle et al., 2002). To this extent, hierarchical linear regression served this study better than other possible approaches by not only examining the effects of group-level

and individual-level variations simultaneously, but also identifying both inter-individual and inter-group variations.

Based on the three-level hierarchical structure of the data, level 1 variables are nested within level 2 and are influenced by level 2 variables. Similarly, level 2 variables are nested within level 3 and share the characteristics of the level 3 unit. Given that patients recruited from each health centre were under the care of the same team of health professionals using similar self-management support strategies (e.g. exercises and booklets), the model was designed for this study in which the regression was assumed to have the same slope (fixed effects) in each of the health centres. Consider the following model for observation at time t (where $t = 0$ and 1 for baseline and three months) patient ij (where $i = 1, \dots, n_j$ for health centre j) within health centre j ($j = 1, 2$ and 3) The three-level linear model for patient's self-management was written:

$$Y_{tij} = \alpha + \beta X_{tij} + u_t + \mu_{ij} + \varepsilon_{tij}$$

where Y_{tij} represents the observed outcome variable at time t for patient i within health centre j , α is the intercept of the regression model, X_{tij} represents patient-level explanatory variables, β are the coefficients for explanatory variables, u_t represents the effect caused by individual, μ_{ij} represents the effect caused by health centre j , and ε_{tij} is an independent residual distributed normally, $N(0, \sigma^2)$, in the population of patients. The model presented above was also referred to as the varying-intercept model (Gelman and Hill, 2006). In this study, self-management of chronic back pain was the dependent variable and the patient-professional partnership was the primary explanatory variable. Pain-related outcomes described earlier in this chapter were also included as other explanatory variables. Meanwhile, patients who completed both baseline and follow-up data collections were considered to be included in this two-level model.

4.5 Constructivist grounded theory study

The inclusion of a complementary qualitative phase in this research study was primarily to explore patients' perceptions and experiences of how their partnerships with health professionals influenced their ability to self-manage their pain. The rationale for the choice of a constructivist grounded theory design has been given in Chapter 3. The following sections explain the procedures carried out for patient recruitment, sample size, data collection and data analysis in this qualitative phase. Alternative methods, where possible, are also considered and choices justified.

4.5.1 Patient recruitment

As the whole study was guided by the explanatory design, as described in Chapter 3, the individuals used in the qualitative phase were those who took part in the initial quantitative phase (Creswell and Plano Clark, 2011). The purpose of this phase was to use qualitative data to provide more detail as well as to explain the initial quantitative results. When patients were shown the separate consent forms after their first screening assessment, they were asked about their willingness to participate in the qualitative interview following the quantitative questionnaires. For those who consented to being contacted about and participating in the interview, a copy of the interview topic guide, developed specifically for patients was provided (Appendix ix), and the author obtained the contact address and phone numbers of these patients. The author, therefore, could arrange a time and place (either in clinics or their homes) for the interview, based on their preference.

4.5.1.1 Inclusion criteria

Patients who met the following criteria were eligible for the qualitative interview:

- Consented to be contacted about the interview;
- Consented to participate the interview;
- Completed both the baseline and follow-up quantitative questionnaires.

4.5.1.2 Exclusion criteria

Patients were excluded if they:

- Had been discharged due to their non-attendance at two consecutive appointments without any contact with the SpineFit service;
- Refused to give their consent to participate in the interview;
- Had insufficient ability to communicate, as identified by health professionals in the clinics.

4.5.2 Sampling

Sampling for qualitative studies is as important as it is for quantitative studies in order to provide unbiased and robust study outcomes (Wilmot, 2005). However, quantitative sampling techniques are not applicable to qualitative studies, as the principle of probability sampling is based on choosing a statistically representative sample from a large population to test predetermined hypotheses and produce generalisable results. Instead, the logic and power of qualitative study sampling lies in selecting participants who can provide rich information, which is of central importance to the aim of the study (Patton, 1990). Moreover, employing quantitative random sampling is inappropriate in qualitative studies, as qualitative studies are conducted mainly to explore people's experiences, perspectives and behaviour. These features or characteristics are unknown prior to conducting the interview and not normally distributed among the participants (Marshall, 1996). The design of sampling techniques for qualitative studies requires the researcher to have an understanding of the unique characteristics of the research participants in order to identify those who are information-rich and thus more likely to provide insight into the research questions (Devers and Frankel, 2000). Within an explanatory design, the sample size for qualitative data collection is often much smaller than it is for quantitative data collection, as the intention is to collect sufficient qualitative information and

understandings to develop meaningful themes, rather than to merge or compare with the data collected in the initial quantitative study. (Creswell and Plano Clark, 2011).

Purposive sampling is frequently employed in qualitative studies. According to Patton (1990), there are 15 different strategies for purposive sampling, including extreme or deviant case sampling, intensity sampling, maximum variation sampling, homogenous sampling, typical case sampling, stratified purposeful sampling, critical case sampling, snowball or chain sampling, criterion sampling, theory-based or operational construct sampling, confirming and disconfirming cases, opportunistic sampling, purposeful random sampling, sampling politically important cases and convenience sampling. As identified in Chapter 3, a constructivist grounded theory design was chosen to guide this qualitative phase, and an important feature of grounded theory is its use of theoretical sampling (Glaser and Strauss, 1967; Charmaz, 2006; Corbin and Strauss, 2008). Theoretical sampling is an emergent process in grounded theory, aiming to elaborate and refine the categories constituting the theory (Charmaz, 2006). It is frequently employed to modify interview topic guides, enabling interview questions to be refocused to collect more specific information relating to an emerging concept (Draucker et al., 2007). Therefore, sampling, data collection and data analysis progress together as concurrent activities, and decisions about sampling should be driven by the emergent analysis and theory instead of being based on predetermined decisions (Draucker et al., 2007). Theoretical sampling is, therefore, distinguished from purposive sampling in which samples are identified prior to data collection. However, some argue that purposive sampling is a practical necessity at the beginning of grounded theory data collection, as the initial sampling decisions are made based on the aim of the research and the general perception of the researcher (Glaser, 1978; Sbaraini et al., 2011). As the research progresses, however, new categories should emerge that drive the researcher to recruit more participants who are likely to contribute to that particular dimension (Schatzman and Strauss, 1973;

Coyne, 1997; Draucker et al., 2007). Thus, theoretical sampling involves the use of purposive sampling in the initial stages.

Based on these principles, a combination of purposive sampling, maximum variation sampling and theoretical sampling were used in this qualitative phase. Purposive sampling, specifically convenience sampling and maximum variation sampling, was initially used to select patients, as this enabled the generation of a variety of categories and themes, which informed later stages of recruitment. Convenience sampling was used for the first four interviews. Patients who met the inclusion criteria and provided consent for the interview were recruited. In order to ensure representation of patients with improved, remained the same, or lowered self-management ability following treatment in the pain clinics, the remaining patients were recruited using maximum variation sampling. Based on patients' responses to the PIH scale measuring self-management ability, they were classified into three groups: improved self-management ability (differences in the PIH $\geq 10\%$), remained the same self-management ability ($-10\% < \text{differences in the PIH} < 10\%$) and lowered self-management ability (differences in the PIH $\leq -10\%$). Finally, theoretical sampling was used based on a variety of themes and categories in data analysis, to select patients for theoretical purposes and theoretical relevance.

4.5.3 Sample size

Unlike in quantitative studies, there is no calculation for predetermining the sample size of a qualitative study. In a study with grounded theory design theoretical sampling normally stops when no new categories emerge, and theoretical saturation is reached. The term "saturation" is used to describe the point at which collecting more data about a theoretical category adds no new properties to it or insights about the emerging theory (Charmaz, 2006, p.189). Therefore, data saturation in grounded theory study implies that no new categories or themes emerge during data interpretation. However, there is still continuing debate about how to recognise data saturation, as no

guidelines are available about what constitutes sufficient data in practice (Morse, 1995). Generally, the sample should be much smaller than those patients recruited in quantitative studies, and fewer than 50 participants are recommended to be involved in a single study with individual interviews (Ritchie et al., 2013). Green and Thorogood (2009) suggested that after approximately 20 interviews, saturation normally appears in an interview-based qualitative study. Creswell (2014) further recommended that 20 to 30 interviews are needed to provide sufficient data for a grounded theory study. Based on these previous suggestions, an initial target of 20 to 25 patients of the 147 patients in the quantitative study was set. As this study progressed, theoretical saturation was used to guide the sample size. Theoretical saturation started to appear after 24 interviews, and the author then conducted two additional interviews to ensure that theoretical saturation had been reached. In total, 26 patients were therefore interviewed.

4.5.4 Data collection

Choosing appropriate methods to collect good quality research data establishes a path leading to valid research outcomes. There are a variety of methods for data collection in qualitative study, and the decision to choose a particular one flows from the research aim and objectives (Creswell, 2014). However this may also be restricted by the setting, design, timing and resources of the research. Three main methods commonly used when collecting qualitative research data are observations, interviews and a review of documents (Patton, 2005; Creswell, 2014).

Observation is the technique of obtaining information based on the researcher's description of existing situations, but with no direct questions being asked (Guest et al., 2013). It requires researchers to observe individuals or groups in their natural state. In qualitative research, observation is a basic technique and can also be embedded within other techniques on most occasions. For example, when the context and setting of a study involving interviews also provides important data, these can

then be recorded through observation. In order to produce good quality data, researchers often spend a long period of time observing and identifying issues or behaviour that are important to their research questions, and they may take extensive field notes about what they observe throughout the whole process (Thomas et al., 2011). One distinct advantage of the observation method is that it provides a more natural environment over an artificial setting, and records participants' actual behaviour instead of what they say they did. However, disadvantages of this method include researchers often having little control over variables that may influence the data, and this may not provide researchers with any deep insights into participants' perceptions or behaviour (Berg and Lune, 2004).

Interviews are recognised as the most common method of data collection in qualitative research, particularly in grounded theory studies (Charmaz, 2003; Gill et al., 2008). Interviewing is a technique used to collect information from participants by asking them questions and getting them to react verbally (Fox, 2006). The aim of conducting interviews is to explore the perceptions, beliefs and experiences of participants on specific issues relating to research questions. Compared with observations, interviewing may provide a deeper insight or understanding of phenomena (Gill et al., 2008). Therefore, it is an appropriate approach to use for studying phenomena about which only little is known or where detailed understandings have to be obtained from participants.

When planning a study involving interviews, designing a topic guide is often the first step in identifying questions that could yield as much information about the research questions as possible. It usually contains a list of the key questions that the researchers would like to cover. The topic guide is then piloted on a few participants prior to further data collection, to ensure its ability to address the aim and objectives of the research (Ritchie et al., 2013). Both the structure of the interview and the questions asked can have an impact on the content as well as the depth of an

interviewee's response. Interviews can be divided into three main types: structured, semi-structured and unstructured. Interviews can also be conducted on an individual basis or with a group of participants, either face-to-face, by telephone and video links, or via an Internet connection (Fox, 2006).

A review of relevant documentary material including laws, regulations, contracts, correspondence, memoranda and routine records on services and clients can be a valuable source of data and information about research questions (The World Bank, 2011). This method is particularly useful when collecting the background and historical context of research participants. Researchers may also gather and analyse documents generated for the participants as a supplement to other methods of data collection in research settings. This method provides researchers with control over which documents are to be reviewed, and can be conducted without disturbing the research setting. However, the researcher's selection and interpretation of the documents may influence final research outcomes (Creswell, 2014).

4.5.4.1 Individual face-to-face interviews

Qualitative researchers may use more than one of the methods listed above to collect the best possible data in order to address research problems. In response to the aim of this qualitative phase, semi-structured, individual face-to-face interviews using open-ended questions were chosen. These allowed the exploration of patients' perceptions and experiences of how their partnerships with health professionals influenced their ability to self-manage their pain. Although data collection and data analysis are presented separately in this thesis, they were conducted simultaneously according to the principles of grounded theory.

As the qualitative study was the second phase of the explanatory design used to guide this whole research project, detailed interview questions could not be framed until the initial quantitative findings were obtained. Therefore, a semi-structured

interview format was selected with a tentative topic guide containing core topics that were developed based on the relevant literature reviewed prior to data collection. Semi-structured interviews provide flexibility appropriate to studies with a grounded theory design, i.e., researchers decide only the general topic or subject areas rather than the specific questions, while participants determine the nature and depth of the information (Duffy et al., 2004; Green and Thorogood, 2009). Researchers are then free to probe certain issues that relate to the research questions in greater depth. For this present study semi-structured interviews enabled the author to start with some general questions relating to patients' chronic back pain and their views of patient-professional partnerships. This approach also provided patients with the freedom to talk about their general and/or specific experiences that they felt were important in influencing their self-management ability. The author then followed up on their responses and probed further into their perceptions and changed behaviour in depth.

Individual face-to-face interviews were chosen in this study for both practical and ethical reasons. Every patient involved in this study experienced different levels of back pain and had different management skills, and it was therefore difficult to select patients with common features for a group interview. Moreover, this study focused on exploring patients' perceptions of patient-professional partnerships, which was the interaction between the individual patient and health professionals. It was again not practical or easy to conduct group interviews involving patients with similar experiences of their patient-professional partnerships and self-management abilities. Patients were also provided with a choice of the time and place where they preferred to be interviewed, making the arrangement of group interviews difficult. The use of individual interviews in this study allowed the author to listen actively to the patients as well as to ask open questions to encourage their participation and explore information in depth, enabling the theory to be grounded in the data (Charmaz, 2006). The selection of individual face-to-face interviews allows more confidentiality and freedom

for patients to express their individual experiences, which could be affected by group interaction and dynamics (Forsyth, 2009). Chronic back pain is a challenging experience, and most patients referred to this service also suffered from mental health problems. Therefore, conducting individual face-to-face interviews in their homes or in a private room in the clinics gave them more privacy and confidentiality in which to talk through their past experiences.

Based on patients' preferences, interviews were undertaken either at the clinics or patients' homes. The purpose of the interview and how it would be recorded were explained to the patients who had agreed to participate; they were also assured about the confidentiality of information and their anonymity. Patients were also informed about the main topics for discussion and the expected length of the interview. The patient's permission was again sought for their participation in the digital recording of interview. Interviews in this study lasted from 15 to 75 minutes and were audio taped using a digital audio recorder.

4.5.4.2 Interview topic guide

A topic guide should be developed in preparation for a semi-structured interview (Hancock et al., 2007). However, it should not be a list of prearranged questions or guidance which would restrict the interview. According to Charmaz (2006), framing questions in grounded theory takes skill and practice, and the questions asked should be able to explore the research questions as well as fit the interviewee's experience. Often, at the beginning researchers ask questions that are sufficiently general to cover a wide range of experiences or behaviour. As the interview progresses, questions need to be narrow enough to elicit and elaborate on the interviewees' specific experiences. Therefore, questions and key points included on the topic guide served as a pool of questions that might be asked during the interview, depending on the emergent categories and themes.

As mentioned earlier, a tentative topic guide including core topics was initiated based on the literature review. Prior to data collection in the clinics, at the suggestion of the author's main supervisor, the topic guide was piloted with a lecturer in the School of Healthcare who had suffered from a lumbar spine injury and pain. This interview lasted 45 minutes. Overall, the interviewee focused on the management of the lumbar pain and the experience of visiting different health professionals. Feedback on the interview was also sought from the interviewee's point of view. Based on this, a final version of the interview topic guide was developed (Appendix viii).

In this study, patients' perceptions and experience of their partnerships with health professionals and their self-management of chronic back pain were two multidimensional phenomena and therefore the topic guide was designed to cover the key points relating to these. In addition, patients were introduced to this study at the very beginning of the interview, and were also asked about their background and circumstances. Issues relating to patient-professional partnerships, the consultation and treatment process, general and specific views of the partnership with health professionals, the best/worst things about this partnership, facilitators and barriers and suggestions were explored. Topics exploring patients' self-management ability included knowledge and information, signs and symptoms, management of pain and its impact and other support services. In order to provide a more in-depth explanation of the initial quantitative results, interview topics also explored the influence of partnerships on self-management ability, and how patients perceived these influences. At the end of the interview, patients were thanked for their participation, and they were provided with the opportunity to ask any remaining questions.

4.5.5 Data management

During this qualitative phase, all signed consent forms were kept in a locked filing cabinet in the author's secure office in the University of Leeds. After each interview, data from the digital recorder was downloaded and stored on a password protected

online university server and then deleted from the recorder. Only research team members had access to these data. The first five interviews from this study were transcribed verbatim by the author for a more in-depth understanding of their information content as well as for further data analysis (Halcomb and Davidson, 2006). Due to time constraints, the rest of the interviews were transcribed verbatim by a professional transcribing company registered with the university. The files were uploaded on to a secure online server and only accessed by a single assigned transcriber. Once the completed transcriptions had been received, the author listened to the interview recordings again to check and ensure the quality and accuracy of the transcriptions. During transcription a serial number was allocated to each patient to ensure confidentiality.

4.5.6 Qualitative data analysis

As justified in Chapter 3, grounded theory was chosen to guide the qualitative phase of this study, aiming to generate a substantive theory explaining the influence of patient-professional partnerships on the self-management of chronic back pain. Consistent with the grounded theory process, constant comparative analysis was used to analyse the data collected from patients with chronic back pain. In this constant comparative analysis, data were transcribed and analysed immediately upon the completion of each interview. Codes, categories and themes were constantly compared between the interviews during each stage of the analysis (Glaser and Strauss, 1967; Charmaz, 2006). Although there are a number of qualitative data analysis methods available, this method provides the best fit to grounded theory methodology as it facilitates in strengthening the process of emerging theory, informs the theoretical sampling as well as building on the growth of the researchers' reflexivity (Charmaz, 2006). Data processing and coding in this study were performed by using QSR International's NVivo 10 software (QSR International, 2012).

4.5.6.1 Coding

In a qualitative study coding generally refers to attaching labels to segments of data that depict the meaning of each segment (Charmaz, 2006). Data are distilled, sorted and grouped by the process of coding. In grounded theory coding, researchers define what is happening in the scene and begin to understand the meaning of it. Researchers create their codes by defining what they see in the data, rather than by applying preconceived codes to the data (Charmaz, 2006). However, coding is an iterative process. Although researchers define and name their codes to capture the empirical reality, they may later refine them as they interact with the participants through studying their experiences in order to understand their statements and behaviour from the participants' perspectives. For this study coding started straight after each interview was transcribed. In the process of coding, the author's questions, prompts and comments during the interview remained uncoded, as the author's utterances were more functional than substantive, prompting the patient to talk through their experiences (Saldaña, 2012). It was also a priority to consider the patient's data, as the purpose of the interviews was to generate a theory by studying their perceptions. Within this thesis, the terms "code", "category" and "theme" were used to clarify the structure of the data. Codes were considered to be fundamental, and each one represented a meaning that was present in the data. As the coding progressed, higher level concepts, designated as categories, were developed summarising and providing theoretical insight into larger segments of the data. Themes were used in this study to identify the highest level structure, which comprised categories with possible relationships. According to the coding strategies recommended by Charmaz et al. (2011), gerunds which are the noun form of the verb, such as "becoming" or "learning", were adopted. This seemed particularly appropriate for this study, as it helped the author to define what was happening in the data and to identify a number of processes of behavioural change linked with patients'

experiences of living with chronic back pain and learning self-management skills. Three main phases of coding were conducted in this study: initial line-by-line coding, focused coding and theoretical coding. The justification for choosing these coding strategies is discussed below. Figures that illustrate the process of coding at each level are presented under each corresponding section.

4.5.6.1.1 Line-by-line coding

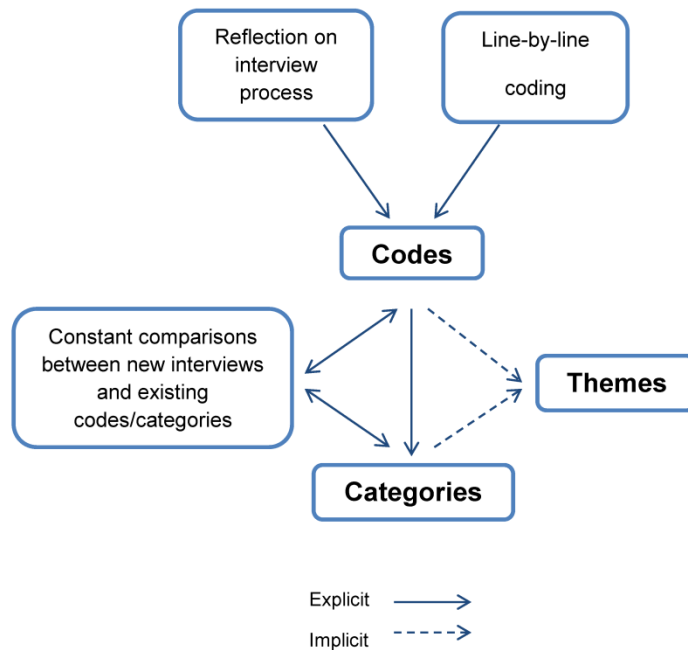
Initial coding is used in all qualitative research to study the main concern being faced by the participants. This may be done through word-by-word coding, line-by-line coding or by coding incident to incident (Holton, 2007). Word-by-word coding requires the researcher to code and move through their data word-by-word. This method may be particularly useful when undertaking a phenomenology study or when studying certain types of data from Internet blogs (Charmaz, 2006; Charmaz, 2014). However, it is challenging when analysing a large quantity of data and the researcher may have to consider the impact of the structure and flow of words on their coding and interpretation. In line-by-line coding each line of the written data needs to be coded (Glaser, 1978). It is most often used as the initial coding strategy in grounded theory. Although not every line contains a complete sentence, this method works well with detailed data that consist of interviews, observations or ethnographies (Charmaz, 2014). Line-by-line coding prompts the researcher to remain open to the data and minimises the chance of missing any important categories. Coding incident to incident is often conducted for making comparisons between incidents. In this way the researcher can compare incidents with previous coded incidents. Generally, coding incident to incident performs better for observational data, as the field notes are written by the researcher themselves and word-by-word or line-by-line coding may not be able to create an insightful theoretical analysis.

In this study line-by-line coding was used as the initial coding strategy because it fitted the purpose of the interviews well - generating a theory explaining the influence of

patient-professional partnerships on the self-management of chronic back pain. All data collected for this study were generated from semi-structured interviews, with the aim of exploring and understanding patients' perceptions and experiences of patient-professional partnerships and the self-management of chronic back pain. Therefore, initial codes for this study covered a variety of topics relating to patients' pain history and the process of building partnerships with health professionals, as well as the skills adopted to self-manage their pain. Engaging in line-by-line coding helped the author to remain open and sensitive to the data, thereby helping to identify implicit concerns and explicit statements from patients' responses (Charmaz, 2014). It also enabled the author to stay close to the data but also to separate new incoming data from categories coded earlier. This may have helped free the author from becoming immersed in these data, which would lead to the failure of the critical and analytical examination of their research data. It also reduced the risk of this study missing any sentence that could produce an important code or category. The author realised that the reading and coding of the data was an iterative process; therefore, a set of codes were always saved for making comparisons as the coding progressed. Each line of the interview transcripts was coded, and these codes were then compared to identify similarities and differences to be further grouped into categories. In this way new categories emerged, and some new codes fitted into existing categories. This coding and emerging process helped to develop the author's conceptual themes towards the discovery of a theory.

Memo writing commenced during this level of coding and continued throughout the analysis. Memos were created to help the author record some data and codes from the patients' views that were considered to be linked with each other. Memos were also perceived to be useful and practical for recording assumptions or reflections that could be explored or compared with subsequent interviews at a later stage. Figure 4.2 summarises the interactions involved in line-by-line coding.

Figure 4.2 Line-by-line coding



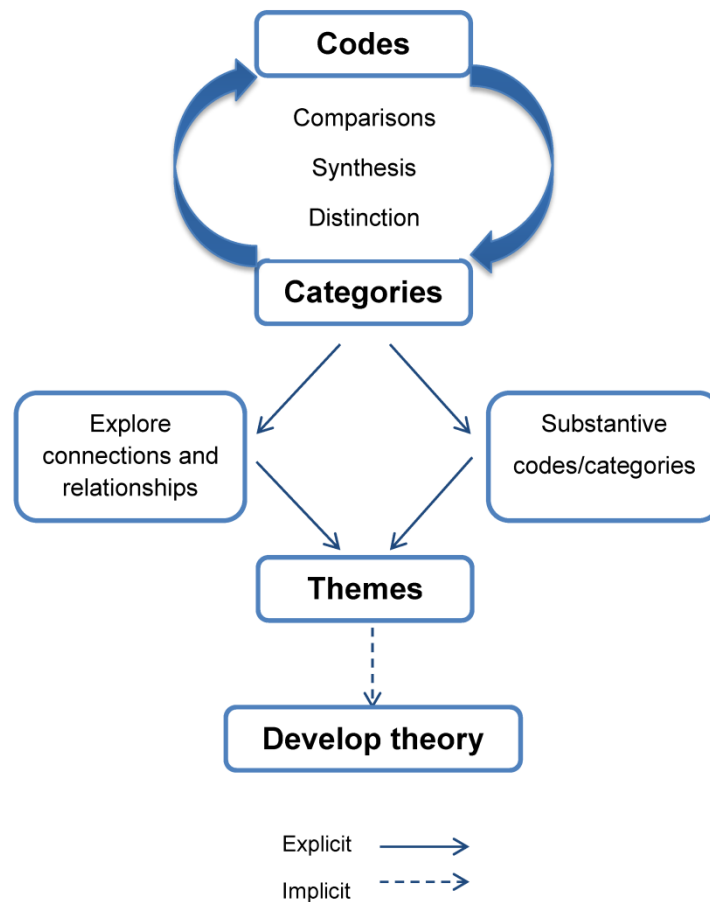
4.5.6.1.2 Focused coding

A rigorous grounded theory study is composed of at least two coding phases: an initial coding followed by a focused coding (Charmaz, 2006). Compared with line-by-line initial coding, focused coding is conducted based on the outcomes of the initial coding, and it concentrates on producing codes that are more directed, selective and conceptual. The purpose of focused coding is to use the most significant and/or frequent codes to synthesise and explain large amounts of data, creating substantive codes and establishing some analytic directions by categorising the data incisively and completely (Glaser, 1978; Charmaz, 2006).

The use of focused coding in this study advanced the theoretical direction of the analysis, enabling the author to act upon the data rather than passively reading them. Through this process, actions, events, interactions and perspectives became more apparent and further linked within the purview of the analysis. During this stage, the initial codes and categories were reviewed and reassessed for their accuracy and adequacy. Comparisons were made between the existing codes and categories to

either synthesise codes (or categories) with similar meanings or to distinguish codes (or categories), if they contained more information, in order to develop the emerging categories. Potential connections and relationships between these categories were explored by re-reading the content of the existing codes and examining the emerging categories. The purposive sampling of participants was continued at this stage to expand and enrich the emerging categories by reviewing their responses to the questionnaires in the quantitative phase. The incoming data were then constantly compared with existing data and applied to develop the relationships between the emerging categories. During this stage, more memos were created to help record how codes and categories related between the initial and focused coding phases. Figure 4.3 summarises the process of coding at this level.

Figure 4.3 Focused coding

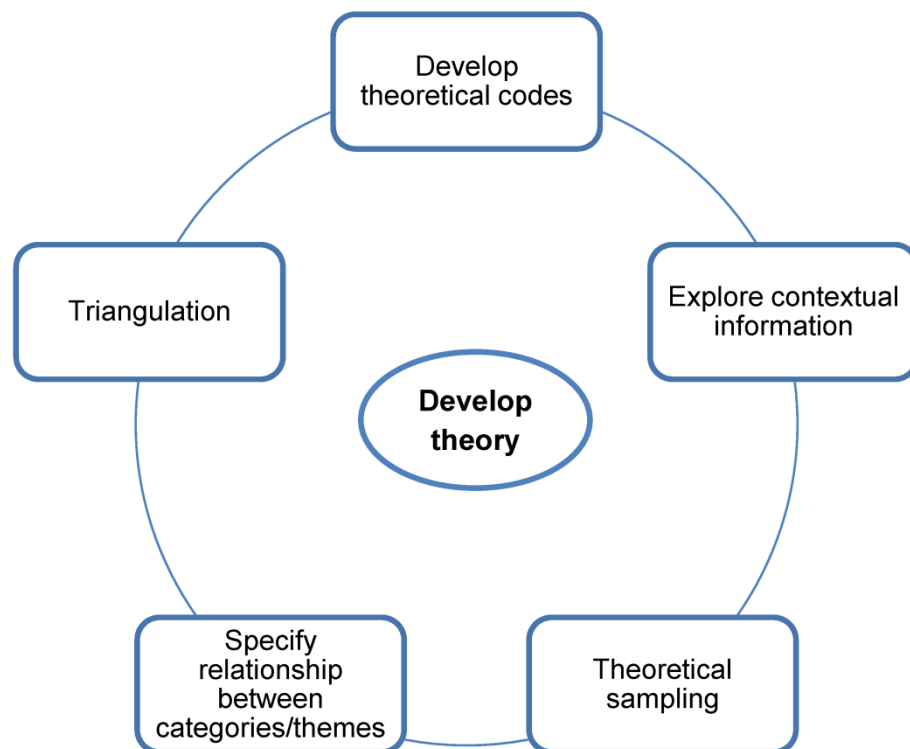


4.5.6.1.3 Theoretical coding

Theoretical coding was originally introduced by Glaser (1978 p.55) as a more advanced method of coding, which aimed to develop theoretical codes that conceptualise “how the substantive codes may relate to each other as hypotheses to be integrated into a theory”. This coding strategy was included in this study because its use helped to specify potential connections between categories/themes that had developed in the previous focused coding process. Meanwhile, these theoretical codes also enabled the author to retain theoretical sensitivity and for the whole analysis process to be coherent and comprehensible towards the development of a theory.

In this stage of coding, more attention was paid to the structure of the codes, categories and themes that emerged in the focused coding level. For categories and themes that had potential relationships, the interview data coded under each category and theme were read and compared. Theoretical sampling was conducted at this stage, with the aim of seeking and collecting pertinent data to elaborate and refine the emerging theory (Charmaz, 2006). Meanwhile, the interviewees' contextual information and previous questionnaire results were reviewed and connected with their particular views and experiences to further investigate whether the emerging theory could explain their results in the quantitative phase. Theoretical saturation was reached during this stage after the 24th interview analysis was completed. Following this, the author re-examined the whole coding structure and confirmed it to be clear and coherent, with each category and theme adding a distinctive contribution to the whole, and the complex relationships between them being thoroughly explored. Figure 4.4 summarises the process of the theoretical coding.

Figure 4.4 Theoretical coding



4.5.6.2 Rigour in qualitative data analysis

Similar to quantitative studies, the establishment of validity and reliability are two necessary steps in the process of qualitative research; however they do not carry the same connotations in qualitative research as they do in quantitative research. Qualitative validity refers to checking the accuracy of the findings by using certain procedures, and qualitative reliability means ensuring that the approach used is consistent across various projects and researchers (Gibbs, 2008). In qualitative literature multiple perspectives and terms have been constructed (Creswell and Miller, 2000). For example, Guba (1981) introduced credibility, transferability, dependability and confirmability to demonstrate the trustworthiness of qualitative research. More recently, Creswell (2014) recommended eight primary strategies, including triangulation, member checking, rich thick description, clarifying the bias, negative or discrepant information, prolonged engagement, peer debriefing/reviewing and external auditor, to enhance the researcher's ability to assess the accuracy of findings as well as to convince readers of that accuracy. For this present study, triangulation, providing a rich thick description, presenting negative cases and peer debriefing/reviewing were employed to ensure the accuracy of findings.

Triangulation refers to the use of more than one approach in the investigation of a research question in order to establish credibility and better understanding (Lincoln and Guba, 1985). Based on the design of this study, a quantitative phase followed by a qualitative phase was undertaken. Therefore triangulation was achieved by first assessing patients' responses to the self-management of chronic back pain and their partnerships with health professionals using quantitative methods, and then by exploring the views and experiences of patients using qualitative interviews to develop emergent theory. The emergent themes and theory were then checked against patients' responses to the questionnaires and found to be useful for building a coherent explanation for the quantitative results.

Rich, thick description refers to a strategy for establishing credibility in a study by providing a detailed description of the setting, participants, methods and themes of a qualitative study (Creswell and Miller, 2000). For this study, a rich detailed description of the research setting, sampling strategy, sample size, interviews, topic guide and data analysis has been provided earlier in this chapter to ensure transparency and to enable readers to decide the applicability of the findings to other settings (Creswell and Miller, 2000).

Although it was expected that a good patient-professional partnership between patients and health professionals would facilitate the development of the self-management of chronic back pain, evidence that provided contradictory information was also sought to ensure that all possible dimensions were covered in the emerging theory. A maximum variation sampling strategy was used to include patients whose responses to the quantitative questionnaires indicated a non-improvement in the self-management of chronic back pain after three-month follow-up. By presenting these negative cases, the emerging theory became more valid (Creswell, 2014).

Peer debriefing/reviewing is a process in which someone who is in a similar research area reviews and raises questions about the study. This strategy enhances the accuracy of the findings by involving an interpretation beyond that of the researcher. In this process, the researcher may be challenged with questions about their methods and interpretations (Creswell, 2014). This was undertaken in this study by involving the author's academic and practice-based supervisors, who reviewed this study from the stage of design to thesis writing. Meetings between the author and her supervisors were scheduled on a monthly basis, during which every step taken to conduct this study was deeply discussed, and feedback was provided based on their knowledge and experiences.

4.6 Chapter summary

This chapter described the process for applying for ethical and research governance approvals, and then focused on presenting a detailed account of the specific methods used in the quantitative and qualitative phases, respectively. Where appropriate, alternative methods were compared and discussed in order to justify the selection of the particular approaches that were chosen to address the research questions. Statistical tests and regression, as well as qualitative coding procedures, which enabled a rigorous data analysis in this study, were also presented. Following this, results from each phase of this study are presented in the next two chapters.

Chapter 5 RESULTS OF QUANTITATIVE PHASE

5.1 Introduction

This chapter presents the results of the quasi-experimental phase in this study. It begins with the description of the study sample recruited at baseline and three-month follow-up, which is then followed by the presentation of their socio-demographic and clinical characteristics. According to the suggestions made on how to interpret the results of the outcome measures in Chapter 4, all outcome measures used in this study were analysed and the comparison of each of these measures was made at baseline and follow-up, by running two-tailed paired parametric or nonparametric tests as required for the type of data. Following this, the results of the hierarchical linear regression are demonstrated, revealing the associations between self-management of chronic back pain and patient-professional partnerships as well as other pain-related outcomes. The total number and percentage are reported for categorical or ordinal, whereas the mean value and standard deviation are reported for continuous variables. Where applicable, both statistically and clinically significant differences are presented by highlighting the p -value and stating recommendations made by the IMMPACT group. Both figures and tables are presented in this chapter to enable a straightforward reading and understanding of the data.

5.2 Study sample

A total of 156 patients were invited to participate in this study, nine (6%) patients declined due to other commitments made following their initial appointments. Consequently, 147 (94%) patients consented to their participation, and all of them had experienced chronic back pain for at least 12 months at baseline. At the three-month endpoint, 103 (70%) patients completed full follow-up data collection. The author quickly checked after each patient completed their questionnaires to see whether each item had been completed. If not, patients were reminded and asked about

reasons for not answering the questions. The major reason reported was the lack of understanding of some questions. The author then explained these questions in lay language without giving any hints on correct answers. This ensured that patients completed every item on every questionnaire, resulting in zero missing data. Their full sociodemographic and clinical information was also recorded without missing data from their medical records held in the pain clinic.

Since this study was designed to take place during routine clinic appointments and not as a stand-alone research study, data could not be obtained from patients who failed to attend for follow-up (n=12) or who were discharged (n=32) according to the clinic attendance policy (patients would be discharged if they did not attend two consecutive appointments without any contact). Binary logistic regressions detected that there were no significant differences in terms of age, gender, employment, pain history, number of pain sites, or comorbidity between those who completed the follow-up and those who dropped out. Therefore, the complete-case method was applied in final regression analyses. Across three health centres, the proportion of patients who completed the three-month interview varied from 60% to 86% (Chi²: 7.02 df: 2, $p < 0.05$). Furthermore, the results of the PIH scale from these 103 patients achieved the power level of more than 99%. Therefore the paired data from these 103 patients who completed both baseline and follow-up data collections were considered for final quantitative data analysis.

5.2.1 Socio-demographics data

Patients recruited for this study were from three health centres. The number of patients recruited from health centre 2 was more than twice that from each of the other two places: 76 (51.70%) from health centre 2, 36 (24.50%) were from health centre 1 and 35 (23.80%) from health centre 3. There were a larger number of female patients: 96 (65.30%) were female and 51 (34.70%) were male. The mean age of the patients was 47.8 years (range: 19-84), of which, 14.30% were 18-30 years old, 17.70%

were 31-40 years old, 25.90% were 41-50 years old, 23.80% were 51-60 years old, and 18.40% were above 60. More than three quarters of the patients were white British (79.60%), and almost half were Christian (46.26%). Eighty-eight (59.86%) patients were married or living with their partners. The proportion of the patients who were unemployed (40.14%) was more than those who remained in employment (full time: 23.13%; part time: 15.65%). Approximately 31% of the patients held no qualification in terms of their educational background, and 71.40% of the patients were non-smokers. Details of socio-demographic data of patients at baseline are presented in Table 5.1.

Table 5.1 Details of socio-demographic data of patients (N=147)

Item	N	%
Health Centre		
1	36	24.50
2	76	51.70
3	35	23.80
Gender		
Female	96	65.30
Male	51	34.70
Age group		
18-30	21	14.30
31-40	26	17.70
41-50	38	25.90
51-60	35	23.80
>60	27	18.40
Ethnicity		
British	117	79.60
Non-British	30	20.40
Religion		
No religion	47	31.97
Christian	68	46.26
Muslim	12	8.16
Other	11	7.48
Unknown	9	6.12
Relationship status		
Married/Civil partnership/Co-habiting	88	59.86
Widowed/Divorced/Separated	33	22.45
Single	21	14.29
Unknown	5	3.40
Employment status		
Full time	34	23.13
Part time	23	15.65
Unemployed	59	40.14
Retired	24	16.33
Other	6	4.08
Unknown	1	0.68
Education level		
Degree, or Degree equivalent and above	13	8.80
A' levels, vocational level 3 and above	9	6.10
Other qualifications below 'A' level, vocational level 3 & level unknown	52	35.40
Other qualifications	28	19.10
No qualifications	45	30.60
Smoking status		
No	105	71.43
Yes	40	27.21
Unknown	2	1.36

5.2.2 Clinical characteristics

All patients had suffered with back pain for at least one year, and almost half of the patients (45.58%) had suffered for at least eight years. The mean duration of pain was 8.3 (SD=8.0) years. Almost 90% of patients had their back pain at multi-sites, and the most common pain locations were lumbar (73.50%) and sacral (87.00%) regions. Patients also reported other comorbidities which they had had before attending the clinic and they were still having. The five most frequently reported comorbidities were depression/anxiety (42.70%), high blood pressure (31.50%), fractures/broken bones (28.00%), osteoarthritis (21.40%) and asthma (20.00%), and more than half of the patients had at least three comorbidities. Before the patients were referred to this clinic, they experienced a wide range of pain-related treatment. The majority of patients took medications for pain relief, with 34% patients who took a single analgesic and more than half of the patients (53.06%) used multiple analgesics. A large number of patients had experienced investigations (79.60%) and physiotherapy (76.20%), however only a small number of patients had experienced spinal operations (22.50%), injections (17.00%) and acupuncture (27.90%). There were 23 patients (15.70%) who had tried other alternative treatments, for example, a transcutaneous electrical nerve stimulation (TENS) machine and chiropractic. The number of different health professionals that each patient visited during the three-month follow-up was also collected. The proportion of patients who received care from two different health professionals was almost the same as those who were treated by more than two health professionals. Details of clinical characteristics of patients at baseline are presented in Table 5.2.

Table 5.2 Clinical characteristics of patients (N=147)

Item	N	%
Pain history (year)		
1-4	55	37.41
5-7	25	17.01
≥8	67	45.58
Single-site pain		
Yes	28	19.10
No	119	89.90
Pain site		
Cervical region	36	24.50
Acromial & shoulders	44	30.00
Thoracic region	48	32.70
Lumbar region	108	73.50
Sacral region	128	87.00
Comorbidity		
Depression/anxiety	61	42.70
High blood pressure	46	31.50
Any fractures/broken bones	40	28.00
Osteoarthritis	30	21.40
Asthma	29	20.00
Number of comorbidities		
0	20	13.60
1	33	22.50
2	19	12.90
≥3	74	50.34
Unknown	1	0.70
Medication taken		
No medication	19	12.93
Single medication	50	34.01
Multiple medication	78	53.06
Investigations		
Yes	117	79.60
no	29	19.70
Unknown	1	0.70
Spinal operations/surgery		
Yes	33	22.50
no	113	76.80
Unknown	1	0.70
Spinal injections		
Yes	25	17.00
no	121	87.30
Unknown	1	0.70
Physiotherapy		
Yes	112	76.20
no	34	23.10
Unknown	1	0.70

Item	N	%
Acupuncture		
Yes	41	27.90
no	105	71.40
Unknown	1	0.70
Alternative treatment		
Yes	23	15.70
no	123	83.60
Unknown	1	0.70
Number of HPs visited in the clinic*		
2	49	47.57
≥3	54	52.43

*: based on patients who completed data collection at both baseline and follow-up (N=103)

5.3 Results of main outcome

5.3.1 Self-management ability

Patients' ability to self-manage chronic back pain in this study was assessed by the PIH scale. As described in Chapter 4, scores on four dimensions and the general index were linearly transformed to a common range of possible values, 0-100, with a higher score indicating better self-management. At baseline, the mean of the total score was 63.25 (SD=14.12), which was increased to 77.62 (SD=11.11) at follow-up. The mean value of each scored question in the PIH scale was also calculated, showing that Q6, the patients' ability to attend appointments was the highest scored item at both baseline and follow-up. Both for Q2, the patients' knowledge of treatment/medication and Q10, the ability to manage the emotional impact showed the greatest increase. The total score of each dimension was also increased by at least 13% with lower variance. Details of patients' self-management of chronic back pain at both baseline and follow-up are presented in Table 5.3.

When comparing the total scores between baseline and follow-up using the paired *t* test, it was found out that there was a statistically significant increase in the total score of patients' self-management ability as well as all dimensions ($p < 0.001$). Each single

scored item was compared by using the Wilcoxon matched-pairs signed-ranks test. A statistically significant increase was found in Q1, Q2, Q4, Q5, Q7, Q9-12 ($p < 0.001$).

Table 5.3 Patients' responses on self-management ability for chronic back pain (N=103)

Question (score range)	Baseline		Follow-up		Difference			p value
	Mean	SD	Mean	SD	Mean	SD	Increased%	
Q1. Knowledge of condition (0-8)	4.25	2.65	5.92	1.91	1.67	2.21	39.27	<0.001b
Q2. Knowledge of treatment/medication (0-8)	3.88	2.38	5.88	1.83	2.00	2.08	51.50	<0.001b
Q3. Ability to take medication (0-8)	6.88	1.85	6.90	1.78	0.02	1.61	0.28	0.675b
Q4. Ability to share in decisions (0-8)	5.29	2.80	7.29	1.31	2.00	2.46	37.80	<0.001b
Q5. Ability to deal with health professionals (0-8)	5.62	2.34	7.43	1.18	1.81	2.23	32.12	<0.001b
Q6. Ability to attend appointments (0-8)	7.73	0.79	7.78	0.64	0.05	0.83	0.63	0.922b
Q7. Ability to monitor and record (0-8)	5.51	2.32	6.21	1.84	0.70	2.11	12.68	<0.001b
Q8. Ability to manage symptoms (0-8)	6.51	1.87	6.60	1.61	0.09	1.82	1.34	0.832b
Q9. Ability to manage the physical impact (0-8)	3.65	2.06	5.03	1.69	1.38	1.90	37.77	<0.001b
Q10. Ability to manage the emotional impact (0-8)	3.47	2.23	5.07	1.89	1.60	1.88	46.22	<0.001b
Q11. Ability to manage the social impact (0-8)	3.68	2.29	5.13	1.98	1.45	2.16	39.31	<0.001b
Q12. Progress towards a healthy lifestyle (0-8)	4.23	2.18	5.27	1.74	1.04	1.91	24.54	<0.001b
Dimension (0-100)								
Knowledge (0-100)	50.85	29.03	73.79	21.51	22.94	23.33	45.11	<0.001a
Treatment Adherence (0-100)	78.16	18.81	89.56	13.77	11.41	17.88	14.60	<0.001a
Recognising and Managing Symptoms (0-100)	73.20	15.25	82.89	11.17	9.68	11.37	13.23	<0.001a
Side Effect (0-100)	44.98	23.82	63.43	20.26	18.45	20.52	41.01	<0.001a
Total score (0-100)	63.25	14.12	77.62	11.11	14.37	11.35	22.72	<0.001a

a: Paired *t* test

b: Wilcoxon matched-pairs signed-ranks test

5.3.2 Patient-professional partnerships

Patient-professional partnerships in this study were measured by the PPIc questionnaire. Questions 1 - 11 are answered with an ordinal scale, ranging from 1 to 5, measuring the partnership between patients and health care professionals. A higher score suggests better partnership. A total score was computed by summing subscale scores that range from 11 to 55. The mean value of the total score of patients' partnerships with health professionals was 37.84 (SD=8.63) at baseline, which was increased to 45.10 (SD=6.81) at follow-up. At baseline, the highest rated ordinal scale question was Q4 "the ability of the doctor/health professional to really listen to you" whereas the lowest rated question was Q5 "your understanding of your health condition". The results showed a similar distribution pattern at follow-up, and

the score for each question was increased and had lower variance. The most improved scores were yielded in Q5 with the measurement of patients' understanding of their pain, and Q10 measuring health professionals' follow up on health care. To detect whether there was a statistically significant difference between baseline and follow-up, paired *t* tests were used to analyse the overall score, and the Wilcoxon matched-pairs signed-ranks test was used for the individual question. A statistically significant difference was found in each question and the overall partnership at 1%. Details of patients' responses on patient-professional partnerships at both baseline and follow-up are presented in Table 5.4.

Table 5.4 Patients' responses on patient-professional partnerships (N=103)

Question (score range)	Baseline		Follow-up		Difference			p value
	Mean	SD	Mean	SD	Mean	SD	Increased %	
Q1 Ask you what you wanted to talk about (1-5)	3.77	1.00	4.19	0.73	0.43	0.99	11.34	<0.001b
Q2 Giving you the information you wanted (1-5)	3.68	1.13	4.15	0.75	0.47	1.06	12.66	<0.001b
Q3 Talking about your concerns and fears (1-5)	3.71	1.10	4.24	0.81	0.53	1.09	14.40	<0.001b
Q4 Ability to really listen to you (1-5)	3.94	1.10	4.37	0.77	0.43	1.21	10.84	<0.001b
Q5 Your understanding of your condition (1-5)	2.70	1.22	3.58	1.01	0.88	1.24	32.73	<0.001b
Q6 Understanding your personal situation (1-5)	3.42	1.11	4.10	0.71	0.68	1.13	19.89	<0.001b
Q7 Patient understanding of healthcare management (1-5)	3.40	1.03	4.08	0.80	0.68	1.06	20.00	<0.001b
Q8 Support for managing your care (1-5)	3.42	1.08	3.98	0.82	0.57	1.14	16.53	<0.001b
Q9 Getting answers to future questions (1-5)	3.27	0.99	3.90	0.81	0.63	1.15	19.29	<0.001b
Q10 Following up on your health care (1-5)	3.19	1.29	4.28	0.77	1.08	1.42	34.30	<0.001b
Q11 Your partnership with your care (1-5)	3.49	0.99	4.22	0.71	0.74	1.04	21.17	<0.001b
Total score (11-55)	37.84	8.63	45.10	6.81	7.25	8.52	19.16	<0.001a

a: Paired *t* test

b: Wilcoxon matched-pairs signed-ranks test

5.4 Results of pain-related outcomes

5.4.1 Pain severity

Pain severity was obtained as part of the administration of the BPI questionnaire, using an 11-point NRS ranging from 0 being "no pain" to 10 being "pain as bad as you can imagine". According to the BPI user guide (Cleeland, 2009), a mean score of the items "worst", "least", "average", "pain right now", and a mean severity score of a composite of the four items was analysed for baseline and follow-up respectively. At

baseline, the mean values of these items were: worst = 7.33, least = 3.99, average = 6.39, pain right now = 5.27 and a mean severity = 5.75. Upon three-month follow-up, these figures were changed to 6.83, 4.05, 5.85, 5.05 and 5.44 respectively. There was a statistically significant reduction detected in patients' worst pain and average pain at 5%, but no significant difference was detected in the other items measuring patients' pain at "least", "right now" or the mean severity of the pain. Details of pain severity at both baseline and follow-up are presented in Table 5.5.

Table 5.5 Patients' responses on pain severity (N=103)

Question (score range)	Baseline		Follow-up		Difference			p value
	Mean	SD	Mean	SD	Mean	SD	Decreased%	
Worst pain (0-10)	7.33	1.75	6.83	1.90	-0.50	1.90	6.89	<0.05b
Least pain (0-10)	3.99	1.90	4.05	2.19	0.06	1.88	-1.46	0.578b
Average pain (0-10)	6.39	1.61	5.85	1.95	-0.53	1.91	8.36	<0.05b
Pain right now (0-10)	5.27	2.52	5.05	2.42	-0.22	2.67	4.24	0.452b
Mean severity (0-10)	5.75	1.58	5.44	1.86	-0.30	1.62	5.24	0.131b

b: Wilcoxon matched-pairs signed-ranks test

Clinically important differences in pain severity were also considered based on the recommendations made for interpreting the clinical importance of treatment outcomes in chronic pain clinical trials (Dworkin et al., 2008). A decrease of 10% up to 30% was considered as a minimally important change, 30% up to 50% as a moderate clinically important difference, and 50% and above as a substantial improvement (Dworkin et al., 2008). Therefore, patients who reported a decrease in pain severity under 10% were classified as experiencing no clinically important change in this study. Similarly, patients' pain was considered to have deteriorated if their scores increased at follow-up: an increase under 10% was considered as no clinically important change, 10% up to 30% as minimal deterioration, 30% up to 50% as moderate deterioration and 50% and above as substantial deterioration. Based on this, seven patients (6.80%) achieved substantial improvement, eight patients (7.77%) showed moderate improvement, 34 patients (33.01%) showed minimal improvement and 26 patients (25.24%) showed no clinically important change. For patients whose results indicated a worse pain after three-month follow-up, 11 patients (10.68%) were considered to

have minimal deterioration, 10 patients (9.71%) had moderate deterioration and seven patients (6.80%) had substantial deterioration.

5.4.2 Pain interference

Life interference was also measured by the BPI questionnaire using 0 (no interference) to 10 (complete interference), with higher scores indicating more severe interference. According to the BPI user guide (Cleeland, 2009), the mean of the seven interference items for patients was calculated to report the overall interference score. The mean value was 6.24 (SD = 1.99) at baseline, which was decreased to 5.65 (SD = 2.41) at follow-up. The results also showed that there was a statistically significant difference in pain interference ($p < 0.01$), general activity ($p < 0.05$), walking ability ($p < 0.001$), normal work ($p < 0.001$), relations with others ($p < 0.05$), sleep ($p < 0.05$) and enjoyment of life ($p < 0.01$). Details of pain interference at both baseline and follow-up are presented in Table 5.6.

Table 5.6 Patients' responses on pain interference (N=103)

Question (score range)	Baseline		Follow-up		Difference			p value
	Mean	SD	Mean	SD	Mean	SD	Decreased%	
General activity (0-10)	6.71	2.25	5.99	2.84	-0.72	2.48	10.71	<0.05b
Mood (0-10)	5.91	2.83	5.87	3.20	-0.04	2.73	0.66	0.606b
Walking ability (0-10)	6.38	2.98	5.58	2.82	-0.80	2.46	12.48	<0.001b
Normal work (0-10)	6.68	2.43	5.91	2.73	-0.77	2.19	11.48	<0.001b
Relations with others (0-10)	4.72	2.98	4.24	2.99	-0.48	2.49	10.08	<0.05b
Sleep (0-10)	7.22	3.03	6.48	3.21	-0.75	2.60	10.35	<0.05b
Enjoyment of life (0-10)	6.05	2.75	5.50	2.99	-0.54	2.66	8.99	<0.01b
Mean interference (0-10)	6.24	1.99	5.65	2.41	-0.58	1.71	9.36	<0.01b

a: Paired *t* test

b: Wilcoxon matched-pairs signed-ranks test

Similar to pain severity, clinically important differences in pain interference are also recommended to use by the IMMPACT group. It is suggested that a decrease of 1 point on the mean of the interference score would be an appropriate benchmark to detect its minimally clinically important difference (Dworkin et al., 2008). However, there was no further information available in order to identify any moderate or substantial differences. The author considered a change below 1 point as no clinically

important difference, and an increase of 1 point and above as deterioration. The mean of the seven interference items was calculated. There were a total of 40 patients (38.83%) who achieved minimally clinically important differences in pain interference, 47 patients (45.63%) did not show any clinically important differences and 16 patients (15.53%) reported a deterioration in pain interference.

5.4.3 Mental health

The mental health status of the patients was measured using the HADS scale, which enabled researchers to measure both anxiety (HADS-A) and depression (HADS-D) simultaneously by yielding a separate score for each. Almost half of patients (48, 46.60%) suffered with both anxiety and depression disorders at baseline, which was maintained at almost the same level (49, 47.57%) at follow-up. Details of patients' mental health status at both baseline and follow-up are presented in Table 5.7.

Table 5.7 Details of results on mental health status (N=103)

Category	Baseline		Follow-up	
	N	%	N	%
Normal	23	22.33	35	33.98
Anxiety Only	25	24.27	16	15.53
Depression Only	7	6.80	3	2.91
Both	48	46.60	49	47.57

5.4.3.1 Anxiety

The result of the anxiety subscale suggested that 30 patients (29.13%) were classified as normal, 30 (29.13%) were mild, 26 (25.24%) were moderate and 17 (16.50%) were severe at baseline. These figures slightly improved to 38 patients (36.89%) as normal, 27 (26.21%) were mild, 26 (25.24%) were moderate and 12 (11.65%) were severe at follow-up (see Table 5.8 for details of the anxiety scores category). Patients' responses to each question on the HADS-A was also compared between baseline and follow-up. A statistically significant improvement was detected in overall anxiety status ($p < 0.05$), having worrying thoughts ($p < 0.05$) and feeling relaxed ($p < 0.01$).

Details of the patients' anxiety disorder at both baseline and follow-up are presented in Table 5.9.

Table 5.8 Details of results on anxiety scores category (N=103)

HAD-A Subscale category	Baseline		Follow-up	
	N	%	N	%
Normal (0-7)	30	29.13	38	36.89
Mild (8-10)	30	29.13	27	26.21
Moderate (11-14)	26	25.24	26	25.24
Severe (15-21)	17	16.5	12	11.65

Table 5.9 Patients' responses on anxiety scores (N=103)

Question (score range)	Baseline		Follow-up		Difference			p value
	Mean	SD	Mean	SD	Mean	SD	Decreased%	
Q1: Feel tense or 'wound up' (0-3)	1.61	0.85	1.61	0.85	0.00	0.75	0.00	0.605b
Q2: Feel like something awful is about to happen (0-3)	1.38	1.05	1.24	0.97	-0.14	0.80	9.86	<0.1b
Q3: Worrying thought go through mind (0-3)	1.71	1.00	1.51	0.93	-0.19	0.89	11.36	<0.05b
Q4: Can sit at ease and feel relaxed (0-3)	1.71	0.79	1.50	0.79	-0.21	0.68	12.50	<0.01b
Q5: Feel like 'butterflies' in the stomach (0-3)	0.84	0.84	0.76	0.77	-0.09	0.84	10.34	0.448b
Q6: Feel restless (0-3)	1.59	0.97	1.52	0.88	-0.07	0.96	4.27	0.433b
Q7: Feel panic(0-3)	1.08	0.88	0.96	0.78	-0.12	0.78	10.81	0.155b
Total score (0-21)	9.92	4.41	9.11	4.36	-0.82	3.39	8.22	<0.05a

a: Paired t test

b: Wilcoxon matched-pairs signed-ranks test

5.4.3.2 Depression

The depression subscale was analysed using the same principle as the anxiety subscale. Half of the patients (48, 46.60%) were in the normal category, 25 patients (24.27%) were mild, 24 (23.30%) were moderate and 6 (5.83%) were severe at baseline. These figures did not change much by the three-month follow-up as 52%, 26%, 18% and 4% respectively (see Table 5.10 for details of depression disorder category). The mean value of Q1, Q2, Q4 and Q5 decreased whereas Q3, Q6 and Q7 increased at follow-up. No statistically significant difference was detected in patient's overall score for depression disorder. However, there is a statistically significant improvement in Q1 "I still enjoy the things I used to enjoy" at 1%, Q4 "I feel as if I am slowed down" at 5% and Q5 "I have lost interest in my appearance" at 5%. Details of

patients' depression scores at both baseline and follow-up are presented in Table 5.11.

Table 5.10 Details of results on depression scores category (N=103)

HADS-D Subscale category	Baseline		Follow-up	
	N	%	N	%
Normal (0-7)	48	46.60	51	49.51
Mild (8-10)	25	24.27	26	25.24
Moderate (11-14)	24	23.30	20	19.42
Severe (15-21)	6	5.83	6	5.83

Table 5.11 Patients' responses on depression scores (N=103)

HADS-D (score range)	Baseline		Follow-up		Difference			p value
	Mean	SD	Mean	SD	Mean	SD	Decreased%	
Q1: Still enjoy the things I used to enjoy (0-3)	1.53	0.93	1.24	0.83	-0.29	0.86	18.99	<0.01b
Q2: Can laugh and see the funny side of things (0-3)	0.70	0.73	0.61	0.74	-0.09	0.69	12.50	0.203b
Q3: Feel cheerful (0-3)	0.80	0.72	0.88	0.77	0.09	0.73	-10.98	0.136b
Q4: Feel slowed down (0-3)	2.15	0.83	1.94	0.93	-0.20	0.83	9.50	<0.05b
Q5: Have lost interest in appearance (0-3)	1.05	1.02	0.90	0.98	-0.15	0.75	13.89	<0.05b
Q6: Look forward with enjoyment to things (0-3)	1.01	0.83	1.02	0.90	0.01	0.82	-0.96	0.856b
Q7: Enjoy book or radio or TV (0-3)	0.83	0.95	0.93	1.00	0.11	0.96	-12.94	0.641b
Total score (0-21)	8.06	4.12	7.53	4.41	-0.52	3.24	6.51	0.103a

a: Paired *t* test

b: Wilcoxon matched-pairs signed-ranks test

5.4.4 Self-efficacy

Self-efficacy was assessed routinely in the pain clinic by health professionals asking patients to rate how confident they were at that particular time. Each patient's scores were added up, producing a mean value of 23.59 (SD=11.29) and 32.99 (SD=12.59) at baseline and follow-up respectively. Due to each item measuring different aspect of confidence, scores for each item were also analysed separately with a mean value being calculated respectively. The score for each item increased by the three-month follow-up, and two of them showed the most increase by more than 50%. Both of them measure patients' beliefs in doing things that they enjoy doing and coping with pain without medication. The results also suggested that there was a statistically significant improvement in total self-efficacy as well as in each scored domain at 1%. Details of self-efficacy at both baseline and follow-up are presented in Table 5.12.

Table 5.12 Patients' responses on self-efficacy (N=103)

Question (score range)	Baseline		Follow-up		Difference			p value
	Mean	SD	Mean	SD	Mean	SD	Increased by%	
Q1: I can enjoy things (0-6)	2.89	1.59	3.71	1.43	0.83	1.30	28.38	<0.001b
Q2: I can do most of the household chores (0-6)	2.69	1.72	3.57	1.60	0.86	1.57	33.06	<0.001b
Q3: I can socialize with my friends or family members (0-6)	2.78	1.69	3.79	1.53	0.98	1.49	36.19	<0.001b
Q4: I can cope with my pain in most situations (0-6)	2.93	1.46	3.57	1.42	0.59	1.39	21.76	<0.001b
Q5: I can do some form of work (0-6)	2.82	1.79	3.57	1.71	0.75	1.38	26.59	<0.001b
Q6: I can still do many of the things I enjoy doing (0-6)	1.95	1.61	3.25	1.58	1.30	1.49	66.46	<0.001b
Q7: I can cope with my pain without medication (0-6)	1.17	1.50	1.78	1.97	0.55	1.43	52.76	<0.001b
Q8: I can still accomplish most of my goals in life (0-6)	2.13	1.57	3.15	1.55	1.03	1.42	47.82	<0.001b
Q9: I can live a normal lifestyle (0-6)	2.32	1.62	3.24	1.64	0.92	1.42	39.63	<0.001b
Q10: I can gradually become more active (0-6)	2.11	1.60	3.42	1.55	1.34	1.61	62.13	<0.001b
Total score (0-60)	23.59	11.29	32.99	12.59	9.39	8.73	39.83	<0.001a

a: Paired *t* test

b: Wilcoxon matched-pairs signed-ranks test

5.4.5 QoL

Like self-efficacy, QoL of the patients was also measured using the DoloTest as routine practice. A total score was calculated for each patient by summing the scores for each of the 8 domains, with a lower score indicating better QoL. Although the mean value of each domain was decreased after three-month follow-up, problems with more strenuous physical activity (for example walking and physical exercise), consistently had the highest score at both baseline (mean=80.47;SD=18.91) and follow-up (mean=63.61;SD=22.95). A statistically significant decrease was found in the total score as well as in each domain ($p<0.01$). Details of DoloTest at both baseline and follow-up are presented in Table 5.13.

Table 5.13 Patients' responses on QoL (N=103)

Question (score range)	Baseline		Follow-up		Difference			p value
	Mean	SD	Mean	SD	Mean	SD	Decreased by%	
Q1:Pain (0-100)	69.86	15.35	62.51	20.48	-7.42	19.40	10.52	<0.001a
Q2:Problems with light physical activity (0-100)	65.33	24.38	52.02	23.62	-13.16	23.24	20.37	<0.001a
Q3:Problems with more strenuous activity (0-100)	80.47	18.91	63.61	22.95	-16.97	22.34	20.94	<0.001a
Q4:Problems doing job (0-100)	26.89	35.02	19.52	28.03	-7.16	26.26	27.40	<0.01a
Q5:Reduced energy and strength (0-100)	71.60	24.31	56.95	23.96	-14.36	24.32	20.46	<0.001a
Q6:Low spirits (0-100)	57.03	25.73	49.73	28.70	-7.08	22.10	12.79	<0.01a
Q7:Reduced social life (0-100)	63.70	26.73	48.05	28.89	-15.78	31.92	24.57	<0.001a
Q8:Problems sleeping (0-100)	73.54	28.59	59.13	29.36	-14.30	25.70	19.60	<0.001a
Total score (0-800)	508.43	117.28	411.53	147.87	-96.22	124.19	19.06	<0.001a

a: Paired *t* test

b: Wilcoxon matched-pairs signed-ranks test

5.5 Results of hierarchical regression modelling

Table 5.14 shows the results of the three-level nested linear regression model examining the associations of self-management ability with patient-professional partnerships and other pain-related outcome measures. After adjusting for age, gender, relationships, education, employment and use of analgesic, multivariate linear nested regressions revealed that self-management ability had a strong positive association with patient-professional partnerships ($\beta = 0.32$; $p < 0.01$) at three months. Meanwhile, the result showed that higher scores for self-management of chronic back pain was also associated with lower pain interference ($\beta = -1.44$; $p < 0.01$), higher self-efficacy ($\beta = 0.28$; $p < 0.05$) and less severe emotional disorders ($\beta = -5.17$; $p < 0.05$).

Table 5.14 Association of self-management ability with patient-professional partnerships and other outcome measures (nested, N=103)

Variables	Self-management			Knowledge			Treatment Adherence			Recognising and Managing Symptoms			Managing Side Effects		
	Coef.	SE	Sig.	Coef.	SE	Sig.	Coef.	SE	Sig.	Coef.	SE	Sig.	Coef.	SE	Sig.
Patient-professional partnership (5-55)	0.32	0.11	***	0.79	0.24	***	0.37	0.18	**	0.38	0.13	***	-0.10	0.16	
Pain severity (0-10)	0.40	0.63		-0.46	1.34		-0.37	0.97		0.56	0.72		1.76	0.86	**
Pain interference (0-10)	-1.44	0.58	***	-0.45	1.23		0.85	0.87		-1.10	0.66	*	-4.10	0.78	***
Self-efficacy (0-60)	0.28	0.11	**	0.11	0.22		0.07	0.16		0.17	0.12		0.66	0.14	***
Emotional disorder															
Normal															
Anxiety only	-2.13	2.35		-8.59	5.09	*	4.83	3.73		0.44	2.65		-6.89	3.32	**
Depression only	-0.73	3.45		-11.62	7.48		7.61	5.51		1.95	3.90		-5.15	4.90	
Both	-4.21	2.40	**	-11.69	5.17	**	2.69	3.78		-0.40	2.72		-12.75	3.36	***
QoL (0-800)	0.00	0.01		0.00	0.02		0.00	0.02		0.00	0.01		-0.01	0.01	
Pain history															
≤4 years															
5-7 years	1.83	2.93		-9.09	5.95		2.87	3.94		5.21	3.50		1.49	3.58	
≥8 years	0.23	2.19		1.68	4.44		2.55	2.94		0.02	2.60		-1.69	2.68	
Number of pain sites															
1															
≥2	2.58	2.54		10.37	5.15	**	4.70	3.41		-1.38	3.02		2.42	3.10	

Variables	Self-management			Knowledge			Treatment Adherence			Recognising and Managing Symptoms			Managing Side Effects		
	Coef.	SE	Sig.	Coef.	SE	Sig.	Coef.	SE	Sig.	Coef.	SE	Sig.	Coef.	SE	Sig.
Number of HPs visited in the pain clinic															
2															
≥3	3.46	2.04	*	8.22	4.15	**	2.19	2.76		5.13	2.42	**	-2.43	2.51	
Medication taken															
No medication															
Single medication	3.75	3.11		10.85	6.32	*	5.45	4.20		3.16	3.69		-2.40	3.82	
Multiple medication	7.11	2.93	**	18.22	5.96	***	8.30	3.98	**	3.92	3.51		1.76	3.61	
Gender															
Female															
Male	1.11	2.15		4.85	4.38		-0.41	2.90		0.96	2.56		0.07	2.64	
Age group															
18-30															
31-40	-5.69	3.56		-3.68	7.23		-13.71	4.79	***	-5.82	4.23		-0.70	4.36	
41-50	2.32	3.06		16.57	6.21	***	-7.65	4.11	*	-0.21	3.65		3.88	3.74	
51-60	3.33	3.19		19.60	6.46	***	-8.68	4.28	**	2.37	3.82		4.09	3.89	
60+	1.17	7.16		3.87	14.51		-5.46	9.60		0.01	8.52		6.97	8.73	
Marital status															
Married/Civil partnership															
Widowed/Divorced/Separated	-1.87	2.81		-4.99	5.70		8.69	3.77	**	-3.97	3.34		-3.68	3.43	
Single	-2.11	2.55		1.36	5.16		0.96	3.41		-6.11	3.02	**	0.14	3.11	

Variables	Self-management			Knowledge			Treatment Adherence			Recognising and Managing Symptoms			Managing Side Effects		
	Coef.	SE	Sig.	Coef.	SE	Sig.	Coef.	SE	Sig.	Coef.	SE	Sig.	Coef.	SE	Sig.
Employment status															
Full time															
Part time	2.60	3.90		-8.84	7.92		12.72	5.26	**	1.99	4.69		3.12	4.78	
Unemployed	2.17	3.05		3.38	6.23		-0.14	4.16		0.28	3.64		5.03	3.78	
Retired	1.36	7.71		7.23	15.64		-0.77	10.35		-1.20	9.22		0.99	9.41	
Other	0.59	5.07		-13.42	10.30		-5.10	6.84		5.30	6.08		4.73	6.22	
Education level															
Higher degree and equivalent															
A-level and above	-1.41	5.61		-12.62	11.45		-1.48	7.65		3.22	6.63		-1.52	6.95	
below A-level	-1.16	3.75		-3.07	7.61		4.24	5.04		2.71	4.56		-7.26	4.59	
Other qualifications	-0.68	3.96		-2.56	8.04		6.71	5.33		2.71	4.74		-7.65	4.85	
No qualifications	0.46	4.01		-5.24	8.14		10.60	5.41	**	3.36	4.78		-6.32	4.92	

Coef: Coefficient; SE: standard error; Sig: significant level

***: $p < 0.01$; **: $p < 0.05$; *: $p < 0.1$

For each of the four dimensions of patients' self-management ability, the results suggested that greater knowledge about pain was significantly associated with better patient-professional partnerships ($\beta = 0.80$; $p < 0.01$) and less severe emotional disorders ($\beta = -11.69$; $p < 0.05$). Unlike other dimensions, knowledge was also the only dimension which was associated with suffering with more than one pain site ($\beta = 10.37$; $p < 0.05$). A trend, but not a statistically significant association was detected between knowledge of the pain and suffering with less severe anxiety disorder ($\beta = -13.38$; $p < 0.1$). Patients' adherence to treatment was found to be associated only with patient-professional partnerships ($\beta = 0.37$; $p < 0.05$). Patients' ability to recognise and manage signs and symptoms of their pain had a statistically significant association with patient-professional partnerships ($\beta = 0.38$; $p < 0.01$) and visiting at least three different health professionals ($\beta = 5.13$; $p < 0.05$). There was a trend towards an increased ability to recognise and manage symptoms in patients reporting less severe pain interference ($\beta = -1.10$; $p < 0.1$), but the association was not statistically significant.

The only dimension which showed no association with patient-professional partnerships was patients' management of side effects of their pain, which refers to their management of the effect of the pain on their physical activity, mood and social life. However, associations were detected between better management of side effects of pain and most of the pain-related outcome measures, including more severe pain severity ($\beta = 1.76$; $p < 0.05$), lower pain interference ($\beta = -4.10$; $p < 0.01$), higher self-efficacy ($\beta = 0.66$; $p < 0.01$), less anxiety ($\beta = -6.89$; $p < 0.05$), and less suffering from both anxiety and depression disorders ($\beta = -12.75$; $p < 0.01$).

5.6 Chapter summary

This chapter presented the results of the quantitative phase of this study. Patients' socio-demographic and clinical characteristics were reported, which was followed by

the details of the outcomes measured. There was a significant improvement observed in patients' self-management ability, partnerships with health professionals, pain interference, anxiety disorder, self-efficacy and QoL at the three months follow-up. The results of hierarchical linear modelling were also reported, indicating that patient-professional partnerships had a positive association with patients' self-management ability of chronic back pain.

Chapter 6 RESULTS OF QUALITATIVE PHASE

6.1 Introduction

This chapter presents the results of the grounded theory study, which is the complementary qualitative phase of this mixed methods study. The qualitative phase aimed to explore patients' perceptions and experiences of the influence of partnerships on their self-management ability to chronic back pain. The rationale and methods for the grounded theory study have been demonstrated in Chapters 3 and 4.

The findings reported in this chapter are based on data from the in-depth interviews and memos written during data collection and analysis. It begins with a description of the socio-demographic and clinical characteristics of the patients involved, which is followed by the presentation of the structure of themes and categories that emerged from constant comparative analysis. Each theme and its related categories are then demonstrated in detail, based on how patients described and reflected on their experiences of living with chronic back pain and recognising changes in their self-management ability. Anonymised quotes from the patients, extracted from the interviews are included to enable a rich understanding of each theme and category. Relationships between themes and categories are also explored, with particular emphasis on the influence of patient-professional partnerships on the development of self-management ability.

6.2 Study sample

The recruitment process followed the completion of the quantitative phase data analysis. The interview topic guide was given to each participant who had consented to this qualitative phase of the study. However, verbal informed consent was still sought prior to each interview following a description of the study and the core topics and after an opportunity to ask questions. All interviews were conducted in a private

consultation room at the pain clinic, and lasted between 25 and 90 minutes. A total of 26 patients who had completed both baseline and follow-up quantitative data collection were recruited in this qualitative phase. As described in Chapter 4, patients were selected purposively based on their responses to the PIH scale that measures their self-management ability, in order to make sure of both the inclusion of patients whose self-management improved and those for whom it had not. As a result of this, 17 patients with increased self-management ability, seven patients who remained on a similar level of self-management and two patients with decreased self-management were invited to take part in the interviews. The patient's ages ranged from 27-69 years old and they had all suffered with chronic back pain for a number of years. More than half of the patients (n=15) had suffered for at least eight years. The majority of patients who volunteered to be interviewed were female (n= 21). Although patients were recruited through three different health centres, the number of patients who were from health centre 2 (n=12) was almost the same as the total from the other two centres (n=14). A total of 15 patients had either full-time or part-time employment, eight were unemployed, two were retired, one was off sick and one was self-employed. Fourteen of the patients had qualifications up to and including "A" levels, and only five had a degree or equivalent. In terms of their marital status, 19 patients were married or living with their partner, six patients were single and only one was divorced. All the participants were assigned a serial number to protect their identity and preserve confidentiality. Table 6.1 below summarises the characteristics of these patients who were interviewed in this study.

Table 6.1 Characteristics of interviewees (N=26)

Patient no.	Age	Gender	Pain history	Self-management ability	Occupation	Education	Marital status
1	52	female	1-4	No change	full time	Other qualifications	Spouse or partner
2	58	female	≥8	increased	full time	Degree or equivalent	Spouse or partner
3	29	female	≥8	No change	full time	Degree or equivalent	Spouse or partner
4	54	female	≥8	increased	unemployed	No qualifications	Single
5	29	female	≥8	increased	full time	Degree or equivalent	Spouse or partner
6	40	male	≥8	increased	unemployed	Below 'A' level	Spouse or partner
7	68	female	1-4	increased	retired	No qualifications	Spouse or partner
8	49	female	1-4	Decreased	part time	Below 'A' level	Spouse or partner
9	43	male	1-4	increased	full time	Other qualifications	Spouse or partner
10	59	female	1-4	increased	unemployed	Other qualifications	Spouse or partner
11	45	female	5-7	No change	full time	Below 'A' level	Single
12	55	female	≥8	increased	unemployed	No qualifications	Single
13	56	female	1-4	increased	part time	Other qualifications	Spouse or partner
14	57	male	≥8	increased	off sick	Below 'A' level	Spouse or partner
15	49	female	≥8	No change	unemployed	A' level and above	single
16	44	female	≥8	No change	unemployed	Below 'A' level	Spouse or partner
17	48	female	1-4	increased	full time	Below 'A' level	Spouse or partner
18	37	female	≥8	increased	full time	Degree or equivalent	Spouse or partner
19	44	female	1-4	increased	part time	Other qualifications	Spouse or partner
20	35	female	≥8	No change	full time	Below 'A' level	Single
21	69	male	1-4	No change	retired	No qualifications	Spouse or partner
22	49	female	≥8	increased	part time	Below 'A' level	Spouse or partner
23	28	female	5-7	Decreased	unemployed	A' level and above	Spouse or partner
24	60	female	≥8	increased	unemployed	No qualifications	widowed/divorced/separated
25	27	male	≥8	increased	full time	Below 'A' level	Single
26	63	female	≥8	increased	self-employed	Degree or equivalent	Spouse or partner

6.3 Structure of the findings

Six themes emerged from the data analysis: suffering from chronic back pain; accessing pain self-management support; building patient-professional partnerships; being supported to cope with the pain; thinking differently about chronic back pain; and seeing a change. Each theme contained a number of categories and sub-categories that emerged from the third and second level of coding in the analysis, as shown in Table 6.2. The detailed description of each theme and category are presented below. Although the author elicited rich data in theme of “suffering from chronic back pain”, only a brief discussion relating to the impact of chronic back pain is presented in section 6.4, as most of its categories have been reported in existing literature. Due to the word limitation, qualitative findings focus in more detail on those later sections in this chapter which present new knowledge. The findings and detailed

themes are presented in a chronological sequence, but it is worth noting that this does not imply a linear progression, nor is it a “one-off” process in patients’ experiences. However the themes and categories presented are a set of connected features of patients’ experiences that may cycle round repeatedly at different stages.

Table 6.2 Structure of themes and categories emerged from the analysis

Themes	Categories	Sub-categories
6.4 Suffering from chronic back pain	6.4.1 Expressing difficulties in life due to the pain	6.4.1.1 Experiencing constant pain 6.4.1.2 Losing certain physical functions 6.4.1.3 Experiencing psychological impact 6.4.1.4 Having other pain-related problems 6.4.1.5 Being trapped in the cycle of chronic pain
	6.4.2 Trying to find solutions before attendance in pain clinic	6.4.2.1 Consulting GP and different health professionals 6.4.2.2 Undergoing investigation and treatment for pain relief 6.4.2.3 Learning and practising exercises 6.4.2.4 Learning skills from peers
	6.4.3 Taking no actions but hoping for the best: letting it be	
6.5 Accessing pain management support	6.5.1 Expecting help to better manage the pain	
	6.5.2 Feeling pessimistic about the pain clinic	
6.6 Building partnerships with health professionals in the clinic	6.6.1 Defining a patient-professional partnership	6.6.1.1 Being necessary to have a partnership with health professionals 6.6.1.2 Requiring contributions from both patients and health professionals
	6.6.2 Facilitators of a good patient-professional partnership	6.6.2.1 Holding desirable attitudes and characteristics 6.6.2.2 Having health professionals to listen and talk with 6.6.2.3 Being understood by health professionals 6.6.2.4 Being able to trust health professionals 6.6.2.5 Being treated as a person rather than a generic patient 6.6.2.6 Having continuous care with particular health professionals

Themes	Categories	Sub-categories
	6.6.3 Barriers to a good patient-professional partnership	6.6.3.1 Lacking sufficient information provided by health professionals 6.6.3.2 Lacking of an individualised approach for the treatment 6.6.3.3 Being treated differently from what patients expected 6.6.3.4 Gaining no benefit or improvement 6.6.3.5 Being given insufficient consultation time with health professionals
6.7 Being supported by health professionals in the clinic to cope with the pain	6.7.1 Holding patients accountable for their pain management	6.7.1.1 Supporting patients to set goals 6.7.1.2 Helping patients find solutions for their pain and other difficulties
	6.7.2 Supporting through providing useful information	6.7.2.1 Explaining: helping patients understand their pain 6.7.2.2 Providing information relating to self-management 6.7.2.3 Having a range of accessible materials to support pain management 6.7.2.4 Providing reassurance
	6.7.3 Supporting through providing physical exercises	6.7.3.1 Suggesting exercises to patients 6.7.3.2 Guiding patients in doing exercises 6.7.3.3 Willing to practise exercises 6.7.3.4 Realising the fact that pain will not cause harm
	6.7.4 Supporting through providing psychological support: helping with stress and depression	
	6.7.5 Supporting through providing holistic care	6.7.5.1 Being supported to change life style: pacing 6.7.5.2 Seeing the whole picture of the patient: helping with other problems
6.8 Thinking differently about their chronic back pain	6.8.1 Facing the reality and accepting the long term pain	
	6.8.2 Reflecting pain management on past experiences	
	6.8.3 Attempting to cope with the pain	
	6.8.4 Understanding the influences of patient-professional	6.8.4.1 Acknowledging the potential influences

Themes	Categories	Sub-categories
	partnerships on self-management	6.8.4.2 Seeing that a good partnership with health professionals would facilitate the self-management of chronic back pain
6.9 Experiencing a change	6.9.1 Feeling positive about the mindset	6.9.1.1 Gaining confidence and competence in managing the pain
		6.9.1.2 Identifying benefits for emotional health
	6.9.2 Making progress on self-management	6.9.2.1 Seeing symptoms improve or stabilise 6.9.2.2 Taking less medication for pain relief 6.9.1.3 Being able to keep track of symptoms and early warning signs
	6.9.3 Finding it possible to lead a normal life	6.9.3.1 Coping better with other pain-related problems 6.9.3.2 Having a better QoL

6.4 Suffering from chronic back pain

Chronic back pain is often regarded as a biopsychosocial condition, which may bring about, not only patients severe physical pain, but also psychological difficulties (Gatchel et al., 2007). Patients recounted how this condition had entirely interfered with their daily life, and how they reacted to carry on their lives with the pain. Patients also shared their stories in looking for every possible solution for pain relief; however they hardly felt any improvement, and lost their hope and attention to it gradually. This theme epitomised patients' difficulties and reactions when they looked backward to their situation and reflected on their past experiences. It also provided a means to obtain broader background information on their life context, enabling both the author and patients to realise that suffering with pain was more than just an unpleasant feeling, but also drove them far away from a normal life style.

6.4.1 Expressing difficulties in life due to the pain

Patients extensively described the nature of their pain – being a long term condition, as well as what the pain felt like in their bodies. They also discussed the negative impact of chronic back pain on their daily lives in various dimensions, including the impact on their mental health, social life and maintaining employment. For example, several patients suffered with serious depression and had been referred to counselling, some were overweight due to a lack of physical activity, they felt drowsy due to the side effects of medications, and one of the patients experienced a stomach ulcer as she had no appetite to eat when her mood was low. The detailed description of major sub-categories under this category is presented below.

6.4.1.1 Experiencing constant pain

Patients described the type of pain that they suffered, for instance, sharp, aching and burning, and highlighted that the pain was constant in certain parts of their bodies. For most of the patients, pain levels varied and could be ascending and descending at

different times. A couple of the patients complained that their pain rating was noticeably raised on cold days. Some patients also reported how the pain started from their experiences, many of which related to injuries, accidents, pregnancy and childbirth, and skeletal muscle weakness in old age. This context also enabled the patients to look closely at how their pain had progressed in the past.

“When I get these sharp pains in me growing, and my bottom, my spine, then this is the one very... just couldn’t move on. You know, basically, leave me alone, that’s it.” [Patient 14, 57 years old male]

“It was killing, you know. It’s like... I feel numbness all the time, it’s tiring all the time as well, you know, my feet, my hips and I can’t walk too much, cos it’s very heavy. I can’t lie down as well, cos when I lie down, it hurts as well.” [Patient 18, 37 years old female]

6.4.1.2 Losing certain physical functions

Pain restricted patients from doing physical movement and activities. Most of them struggled with simple activities, including walking, cooking and cleaning because of the pain they experienced whilst doing these tasks. The fear of pain then led to the avoidance of the physical movement and activities that could produce more pain. However, such avoidance resulted in a lack of strength, energy, and a feeling of failure to do some form of housework and leisure activity. This may develop further towards total avoidance of physical activities and progress to interference with physical functioning. However, patients’ responses to the interference varied, and some still pushed themselves forward and tried to fight against the pain.

“Because I am such an active person, but I didn’t know what else to do. You get this mind set of, you know, you in pain, you got to stop doing what you doing, which I did. I stopped going on my walks...but I don’t allow it to stop me doing anything. I work full time, I do extra

hours as well, so... I won't let it beat me." [Patient 11, 45 years old female]

6.4.1.3 Experiencing psychological impact

Previous literature also highlighted that chronic back pain is associated with psychological distress in general (Schmidt et al., 2012). In this study, patients recounted that suffering with pain for a long time affected their mental health in a negative way, which could lead to anxiety and depression. For example, some patients had been through counselling services and some were still taking antidepressants. This was attributed mainly to the failure of completing routine activities, but also partly due to a lack of understanding and competent support from the people surrounding them, including friends and employers. Therefore several patients claimed to hide their pain and pretend that they could take control of it. However, it was possible that this experience stimulated the occurrence of psychological distress afterwards, particularly when they were alone.

"Yes, I go to shed, kicking shed, you know, swear at myself. You know, get mad inside yourself, but not the people around me in family and my friends." [Patient 14, 57 years old male]

In turn, some patients also discussed how anxiety and depression could be an influence by intensifying or decreasing the feeling of pain.

"I think that depression plays obviously a huge amount in pain... plays a huge part in pain." [Patient 1, 52 years old female]

6.4.1.4 Having other pain-related problems

Not only has chronic back pain interfered with patients' physical and mental health, but also resulted in difficulties in a wide range of circumstances, including diet, social activities, and sleep patterns. For example, they struggled with being involved in social activities and falling asleep. Some reported that they suffered with side effects

of their daily medications, which caused them drowsiness and stomach problems. Other patients talked through their undesirable experiences, which were fundamentally related to the restriction in both their physical and psychological health conditions.

“I have to take the medication, and also I don’t really eat properly as well, cos of this depression and stuff. So that’s why I got this stomach problem and also the ulcer.” [Patient 18, 37 years old female]

Moreover, patients chose to avoid some forms of social activities, where they were concerned it would escalate the pain and that they had no solutions for it. Instead, patients would rather be left alone, which could increase the degree of self-disappointment and psychological distress. Similarly, patients found that it was a struggle to work full time or even remain in their employment. This seemed to be mainly related to their limited physical functioning as well as sickness absence. Consequently, financial difficulties also became one of the patients’ main concerns.

“Now you see I can’t work anymore; they actually tried to get rid of me, as there you’ve got people living with dementia, cos I couldn’t do moving and handling, because of my pain.” [Patient 10, 59 years old female]

Being in constant pain implies that pain affects patients’ normal lives during both day time and night time. Most of the patients described their experiences of disturbed sleep patterns, and several expressed that they could hardly sleep when they were in pain. It was also considered as another sign of getting stuck in a cycle of pain, in which a lack of sleep could link with other symptoms, including fatigue and anxiety.

6.4.1.5 Being trapped in the cycle of chronic pain

Patients suffering from chronic back pain often described that their problems were compounded by additional difficulties; therefore the sub-category which emerged was

to describe how patients perceived their back pain to be associated with other problems. In most cases, this cycle started with the physical pain in certain sites, and then spreading to interfere with a patient's life. Consequently, patients were likely to feel frustrated or anxious leading to emotional distress, which in turn could cause more pain. Following this path, patients gradually became more inhibited about using their body or carrying on their life normally, which then made them vulnerable as well as increasing the risk of a wide variety of other health problems.

"You sometimes get into that frame of mind and it's like a vicious circle, you just can't get out of it. And when your mood's low again you can't get out of it. You need to... you know you need to, but you can't. So I'm sort of on that track at the minute. [Patient 17, 48 years old female]

"Then the circle, when you get really down and hit rock bottom, which I'm just coming out of a little spiral that I had, you hit rock bottom and then you're back to square one." [Patient 24, 60 years old female]

As many of the patients interviewed had had pain for a number of years, the above difficulties reinforced their feeling that they were living with a long term illness. This drove them to start looking for solutions, which is explored in the next category.

6.4.2 Trying to find solution before attendance in pain clinic

Although patients remarked how their lives were negatively affected by chronic back pain, which they had been struggling to accept previously, they also went through a process of seeking solutions and treatment. Generally, patients sought help and action from the following resources: consulting GP and other health professionals, learning and practising simple exercises, trying a range of alternative treatment and learning skills from peers.

6.4.2.1 Consulting GP and different health professionals

All patients had the experience of consulting their GPs with an initial episode of chronic back pain for pain relief and pain-related treatment, since the GP in primary care predominantly prescribed medications and made decisions about patients' referrals to secondary care. However, it was rarely commented by patients that they were satisfied with their experiences with the GP, which was largely due to not being understood by the GP and the limited consultation time given. This was also linked with barriers to building patient-professional partnerships explored further in section 6.6.2.

“She [GP] gave me these medications and put me on the morphine. It gets to the stage that I take all medications all day long. I take 91 pain killers a week on top of other medications that I've got.” [Patient 14, 56 years old male]

Many patients also underwent treatment with other health professionals, mainly from secondary care and private treatment. Yet, there was a lack of confirmed diagnosis or sufficient explanation about the cause of the pain, and the treatment process was rather slow, leading to financial problems for some of the patients.

“I went to see many many kinds of doctors, like Chinese doctor, Japanese doctor, Thai doctor, even went to the temple, and English doctor, American doctor. It's just not gone. And my mum paid so much money on just this. And no one found what happened to me. [Patient 18, 37 years old female]

6.4.2.2 Undergoing investigation and treatment for pain relief

A number of patients were referred for investigation to find out the cause of the pain as well as receiving relevant treatment for pain relief. However the results were not

often very helpful as the most of the patients were told that their MRI appeared normal or showed non-specific spinal disease.

“They’ve sent me for numerous tests on other things to try and decide what the pain was. They sent me to rheumatology; I’ve had my shoulder injected and my leg injected with cortisone, then that came back negative. And they can’t really pinpoint anything.” [Patient 17, 48 years old female]

The most commonly reported treatments were taking medications, receiving spinal injection or surgery and using a TENS machine. However, some patients reported suffering negative side effects as a result of the treatment interventions, producing more pain and other health problems. There were also a couple of patients who received almost every available treatment suggested by their GPs; however nothing seemed to relieve their pain on a long term basis.

“Yeah, just put the Butrans patches on, took the pain killers, had the injection before and did the exercises that physio gave to me, and that was it really. And nothing seemed to work.” [Patient 20, 35 years old female]

6.4.2.3 Learning and practising exercises

Patients were also recommended some basic exercises by their health professionals before attendance in this pain clinic. However they found that the benefit of these exercises was rather limited, as either no improvement was observed or more pain or discomfort was produced afterwards. Gradually, patients lost their confidence as well as patience in practising the exercises. Some patients also detailed the way exercises were delivered by their health professionals, in which they were guided and considered as passive recipients without being provided with sufficient explanations. This seemed to have a negative impact on patients’ willingness to try the exercises.

“Yes it’s do this, do this, do this, do this, and that will help you out, but they don’t want to know if it isn’t helping you out.” [Patient 4, 54 years old female]

6.4.2.4 Learning skills from peers

A number of patients mentioned that they sought support and help from other resources, including websites, magazines and their families or friends who had similar experiences. As living with chronic back pain could be an isolating experience, reading others’ stories and sharing experiences with other people with chronic conditions was a powerful practice that reduced this isolation. Meanwhile, this enabled them to accept the nature of chronic conditions, and also gain confidence and possible solutions from others.

“You take information from all these other people who are peers, they’re not professionals, they’re just peers and this works for me, this works for me.” [Patient 1, 52 years old female]

Although the majority of patients remarked how hard they had tried to control the pain in numerous ways, they could only receive limited benefit for a short period of time. The combination of suffering for the long term and seeing no further improvement more or less underpinned their responses and undermined their confidence in coping with the pain.

6.4.3 Taking no actions but hoping for the best: letting it be

A number of patients struggled to continue managing their pain after they experienced different treatments but with little benefit. This led them to give up what they were doing and block out what was happening rather than focus on finding new directions. Based on their experiences, this was partly related to the diagnosis of unexplained chronic back pain and the lack of relevant information and knowledge.

For both health professionals and patients, unexplained chronic back pain could not provide reliable evidence on the most appropriate treatment, which was echoed in the sub-category 'Undergoing investigation and treatment for pain relief' in 6.4.2.2. Patients therefore received gentle support or care for non-specific back pain, for example, taking pain killers, lying in bed and doing mild exercises. However the lack of certainty in the diagnosis in turn also caused concerns and anxieties about the appropriateness and accuracy of these solutions, particularly when there was no obvious positive effect observed afterwards. Furthermore, patients recounted that they did not have sufficient information or knowledge to manage the pain properly before attendance in the pain clinic.

“No, I didn’t know (started crying). I didn’t know what to do; it’s like I didn’t know where to go. Even my parents, no one understand that.”

[Patient 18, 37 years old female]

Although patients struggled to cope with pain and other difficulties, some of them were still positive and held a strong belief in seeking for alternative treatments. This optimistic attitude was also largely related to their referral to the pain clinic, which is explored in the next theme.

6.4.4 Theme summary

Patients expressed the fact that chronic back pain had interfered with almost every aspect of their lives, primarily focusing on the impact on their physical and psychological status. This left patients in situations where they felt trapped in an invisible cycle. Patients realised the negative impact of their condition on their mood, as they were frustrated and anxious because of the pain. Patients also shared their experiences of trying to find solutions to cope with the pain. However they could only gain limited benefit from these, and nothing seemed to work on a long term basis. As a result of this, some patients found that it was too difficult to take a further step.

Meanwhile, they realised that there was no specific diagnosis available for their pain, and therefore they did not have the accurate information, knowledge and skills to manage the pain in a proper way. However patients still stayed optimistic and believed that there were alternative treatments, which led to their referrals to the pain management clinic.

6.5 Accessing pain management support

Given that patients felt they only received limited support and benefit from their GPs and other health professionals, they had been referred to the chronic pain management clinic, where patients were mainly supported to better manage the pain instead of being provided with immediate pain relief as desired by most. Generally, patients described two main reactions on being referred to this clinic: expecting help to manage the pain and feeling pessimistic about the clinic.

6.5.1 Expecting help to better manage the pain

For patients who were relatively optimistic and self-determined, being referred to the pain clinic could be seen as a form of help, leading to a step forward and also leading to a potential change in how they would be able to manage their chronic back pain. It was also considered as an external resource which could enable patients to access alternative treatment and learn skills to cope with the challenges of their condition. Patients had expectations about how they would be treated and possible health outcomes.

“I can’t say I was really doing a whole lot to manage it myself. It was more about, well, I need someone to help me manage it. And I suppose now I can, which is probably the aim and objective of the whole thing.” [Patient 5, 29 years old female]

6.5.2 Feeling pessimistic about the pain clinic

Conversely, for patients who struggled to cope with the pain and also had extensive experiences of different treatments, they considered being referred to the pain clinic as an intervention that was likely to have limited benefit to that which they had undergone previously. As a result they lacked confidence in health professionals and further treatment in the pain clinic. However, patients claimed that this was largely related to their lack of understanding about this clinic and awareness of how it could help patients manage the pain.

“I’ve had normal physio for 12 months. I felt I’d not really got much out of that, and when Dr Glyn suggested I see SpineFit I thought, well it’s just an extension of physio, I thought, well give it a go, but I wasn’t that optimistic when I first started.” [Patient 19, 44 years old female]

“Because I didn’t know anything about this service before when I was sent there, I was a bit shocked. You know? No physiotherapy? Because you were just so used to that.” [Patient 13, 56 years old female]

6.5.3 Theme summary

Within this theme, patients recounted their reactions of being referred by their GPs to the pain clinic for self-management. The two main reactions discussed were based on their attitudes towards pain management as well as their previous experiences of coping with the pain. The following explores how patients and health professionals worked together to promote patients’ self-management ability in relation to chronic back pain, from patients’ experiences and perceptions.

6.6 Building partnerships with health professionals in the clinic

After receiving care and treatment for more than three months in the pain clinic, patients talked extensively about their experiences of and understandings about, the

service. Due to the nature of the pain clinic health professionals worked to help patients manage chronic pain by providing support and advice to help improve their QoL, rather than interventions to cure the pain. Patients realised the importance of themselves being part of and playing an active role in their pain management along with health professionals' support. To address the aim and objective of this study, patients also focused on sharing their perspectives on patient-professional partnerships, as well as identifying the facilitators of and barriers to building a good partnership with health professionals.

6.6.1 Defining a patient-professional partnership

Patients were initially asked about their general opinions and personal views on a patient-professional partnership. In a qualitative study, it was considered as being essential to obtain and appreciate the participants' subjective understandings of a particular phenomenon that may further influence their behaviours and judgement. Here patients provided an account of their desired patient-professional partnerships, which for them, seemed to be criteria in regards to how they then measured and commented on the partnerships they developed with health professionals in the clinic.

6.6.1.1 Being necessary to have a partnership with health professionals

Patients expressed their general opinions on the practicality of patient-professional partnerships. All the patients highlighted that it was necessary to have a good partnership with their health professionals, not just in the pain clinic, but also elsewhere. They perceived a positive partnership with health professionals as the basis of being supported to self-manage their condition as it enabled patients to feel comfortable in speaking out about their difficulties and asking for help.

“It’s [a patient-professional partnership] such a necessary thing that people need to learn. That’s the only thing. Give them (health

professionals) a pay rise, they work bloody hard.” [Patient 15, 49 years old female]

“I just hope it does for other people as well because I think it’s necessary. It’s another side that definitely the NHS should continue with.” [Patient 1, 52 years old female]

Alongside the positive attitudes towards having a partnership with health professionals, on the other hand, a couple of patients were also aware of the potential negative impact of such a close partnership on the quality of their health service. They were concerned whether health professionals would control the whole treatment process rather than following the standard procedures when they had a close partnership.

“So it’s critical that you get on with the guys and that they’re more sort of flexible and proactive with the way they work rather than do what they are supposed to do, if you know what I mean.” [Patient 5, 29 years old female]

6.6.1.2 Requiring contributions from both patients and health professionals

Patients advocated that it was a prerequisite that both patients and health professionals make contributions and share responsibilities in order to establish and maintain a partnership. In this clinic, health professionals offered a range of pain management skills and supported patients to identify approaches to pursue a better life living with pain. As a partnership, patients also needed to play an active role and cooperate with health professionals and to follow up on their suggestions.

“Because I think if you don’t get on with the team you don’t respond to the conversation you’ve had; you don’t take in the knowledge they’re sharing; you don’t understand the reasons why they’re sharing what they’re sharing. And at the same time if they’re not going to listen to

you and they're not going to help you with the emotional side of things, then you can't get out of that cycle." [Patient 5, 29 years old female]

Moreover, some of the patients expressed more specific expectations. For example, it was highly likely for them to develop a good patient-professional partnership with the one health professional they visited the most frequently, emphasising the importance of continuity of care. Details are explored in the next category.

6.6.2 Facilitators of a good patient-professional partnership

Based on their experiences in the pain clinic, patients identified six key factors that would facilitate the development of a good partnership between patients and health professionals. These facilitators included: holding desirable attitudes and characteristics, having people to listen and talk with, being understood by health professionals, being able to trust health professionals, being treated as a person rather than a generic patient, and having continuous care. The above facilitators were listed separately in no particular order, but they were closely linked with one another in patients' experiences. Details are explored in the following sub-categories.

6.6.2.1 Holding desirable attitudes and characteristics

Within this sub-category, patients identified a set of desirable attitudes and characteristics of both health professionals and patients that could enable the initialisation of a partnership.

6.6.2.1.1 Being a health professional

Patients placed an emphasis on the importance of certain attributes and characteristics of the health professionals in a patient-professional partnership. These included: being professional and knowledgeable, being friendly and sympathetic, and being willing to spend time with patients to work with them to solve their problems.

Being professional and knowledgeable enabled patients to appreciate the expertise and skills of the health professionals, which was also likely to influence patients' understandings of their health problems and further build patients' trust in their health professionals.

“What they need is to make sure they keep up the quality of the staff that they’ve got and don’t take people who are lesser qualified, because if they get people who are lesser qualified than they are now the whole thing is just going to go [down] ... Because they won’t have that same attitude and the same input that these staff give it. [Patient 15, 49 years old female]

Meanwhile, health professionals' behaviour, such as showing respect, being friendly and sympathetic toward patients, were identified as facilitators of a good partnership, in which patients were able to feel relaxed and open to discuss their difficulties and to ask for help.

“The way that she [health professional in the clinic] leads herself, you know, she has the empathy, she has the compassion. She’s not patronising, she’s giving you ideas. [Patient 11, 45 years old female]

Many patients commented on the value of the need for health professionals to be patient, with the willingness to spend time with and to help them to solve problems. Some of them emphasised how health professionals could help them psychologically in this approach when offering sufficient time to listen to and talk with patients during each session, for example, patients felt calmer and less distressed after having an insightful conversation on their pain and other life difficulties. This was also closely connected with the next sub-category (6.6.2.2). Moreover, comparisons were also made between GPs and other health professionals in the clinic by many patients in order to highlight the importance of enough time being given to patients with chronic illnesses. Some recounted feeling rushed by their GPs.

“They’ve been so patient and calm, and, you know, despite the fact that I’ve been quite upset at times, they’ve been quite logical and rational with me.” [Patient 5, 29 years old female]

“I feel better here because I think they give you more time, whereas when you are with doctors, you are in for about 5 or 10 minutes, then you out again. However when I was here, they take the time, they are not rushing. So you can discuss things more.” [Patient 16, 44 years old female]

6.6.2.1.2 Being a patient

By acknowledging the need of contributions from both health professionals and patients in a partnership model of health care, patients described a cooperative patient as one who needed to accept the nature of the pain, hold positive beliefs about the outcomes, and provide accurate feedback on treatment effectiveness.

Acknowledgement and acceptance of the nature of their chronic back pain is often considered as the first step towards self-management and it may continuously inspire many to learn further (Fu et al., 2015). Patients who accepted that their pain was a long term condition were able to focus on exploring new directions to manage the pain appropriately, rather than disregarding their difficulties and pursuing a permanent cure. Through cultivating the acceptance of their chronic back pain, patients were more certain about and also prioritised the need for self-management in the present moment.

“That’s what I needed really because, you know, it [pain] is what it is; it’s not going to disappear anytime soon. So I need to just... it’s about managing what’s there. [Patient 5, 29 years old female]

“I’m going to be able to understand my pain and I’ll be able to accept my pain and manage it in the long run, I’m going to be able to

manage my pain, and just accept it's going to be there and not just to disregard it.” [Patient 23, 28 years old female]

Although suffering from the pain and facing difficulties for a number of years that may overwhelm or weaken the patients' confidence, patients expressed the need for themselves to be optimistic and think positively about the health outcomes, in order to cooperate and work with health professionals in a partnership.

“I'm being optimistic, so I'm not just going to forget, I'm not just going to give up. I'm going to try... I'm going to try my hardest and hopefully...” [Patient 23, 28 years old female]

“Stop stressing about the things you can't control, worry about the things you can control. And I keep... every time I feel really crap with myself I think of that.” [Patient 24, 60 years old female]

Some of the patients further highlighted the importance of providing accurate feedback to their health professionals with respect to the effectiveness of the treatment, for example, whether they felt better after practising Tai Chi or Pilates. Health professionals could then review their care plans and make further recommendations towards the desired goals.

“You know, I have to be honest with them, because if I am not, if I come back and go “yes, I did all of them”, but I am still in pain, then it doesn't work out. If you give her the wrong information, then she's [health professional] gonna give me wrong information, and I am gonna go away with that wrong information, so it doesn't make sense then.” [Patient 11, 45 years old female]

6.6.2.2 Having health professionals to listen and talk with

In a good patient-professional partnership, patients expected their health professionals to listen to their stories and talk about their anxieties, fears and other

difficulties in life. Through effective communication, health professionals would be able to identify patients' health priorities and needs and provide advice suitable to their specific situations. For example, one patient noted that health professionals in the clinic were "*adaptable, they talked and they listened and they said well we'll try this then*" [Patient 12, 55 years old female]. As a result, patients would feel relaxed and more able to discuss their concerns and anxieties in regards to their condition, which may benefit them psychologically.

6.6.2.2.1 "Listening to me"

As chronic back pain was perceived by patients as a long term condition and they may have visited a number of different health professionals and repeatedly provided a history of their problem and associated pain and actions, patients often lost interest in re-explaining their problems or history of pain in detail. They reported feelings of not being listened to or cared for. However, this feeling was positively addressed by this clinic, in which patients were given time and listened to. It was also considered as an essential facilitator from patients' perceptions if they were given a chance to talk and feel that their concerns were listened to. These were considered by patients to be an essential facilitator of a good partnership.

"They are good listeners. She [health professional] listens to me about everything. Emm, but not only that, they have some advice, you know, which is what you need." [Patient 11, 45 years old female]

"So for me it's much more about the fact that these [health professionals] are happy to listen and help you get out, mentally out of your cycle than trying to fix any sort of pain." [Patient 5, 29 years old female]

6.6.2.2 Talking is a cure

Whilst health professionals might make a number of suggestions relating to how the patient could self-manage their pain, what was more important was the manner in which they spoke. Patients reported taking more notice of how the health professionals talked to them, it was this which enabled patients to talk about their difficulties and life stories in a more open and comfortable environment.

“I think they are good, because they do talk to you properly. They don’t...you know, even though you hadn’t done very good, they don’t talk down to you, they still, you know, they still encourage you to do what you are supposed to do.” [Patient 10, 59 years old female]

6.6.2.3 Being understood by health professionals

Having smooth communications with health professionals when patients were listened to was recognised as the basis for another facilitator of a good patient-professional partnership – being understood. It was suggested by patients that they expected health professionals to understand their situation and advise accordingly after listening to their personal stories. These stories were based on patients’ personal knowledge and understandings of the development of their condition and other potentially related difficulties. Patients then would be understood and naturally feel close to health professionals who seemed to “have similar experiences” and appreciate how the whole process developed.

“It’s quite important to me because I feel if they don’t understand what’s wrong with me, like how I’m feeling, then they’re not going to be able to help me.” [Patient 23, 28 years old female]

“I don’t know whether they’ve experienced it personally with back pain and stuff, but I certainly felt like they knew where I was coming from

do you know what I mean, with my back pain.” [Patient 19, 44 years old female]

Some patients described that they felt safe when health professionals understood their situations, since they could share some issues about their personal lives with their health professionals but not necessarily with other people. This may result in a major benefit for patients’ psychological health status.

“It’s like well, you know, coming here, and sitting down, talking to her [health professional], it’s safe.” [Patient 11, 45 years old female]

“I’ve said things to her [medication management nurse] that I didn’t ever thing I’d say to anybody. I’ve said her since obviously to... but that, the way she made me feel made me safe to say things.” [Patient 24, 60 years old female]

6.6.2.4 Being able to trust health professionals

A number of patients believed that there had to be a level of trust when patients and health professionals had a good patient-professional partnership. Patients were able to trust their health professionals when they felt they were listened to and understood. Some identified that they started developing their trust in health professionals to a large extent when they gained benefit from the treatment and management skills provided by those health professionals. Furthermore, patients may worry less about their conditions and be more confident to self-manage since they counted on their health professionals to provide appropriate treatment and management skills.

“If you trust that person and know what they’re saying is right and that you need to do it [self-management], then you’re more tempted to do it, than if you don’t trust that person and think that’s a load of rubbish that you’re telling me.” [Patient 17, 48 years old female]

6.6.2.5 Being treated as a person rather than a generic patient

Another important factor identified by patients which may help build a good patient-professional partnership is that patients expected to be treated as an individual rather than as one of the generic patients with chronic back pain. Although patients referred to the pain clinic had many symptoms in common, they preferred to be treated with individualised approaches that were tailored to their life context and preferences. Through this, patients were able to understand that it may be achievable to manage their pain and other difficulties in daily living activities, leading to greater motivation.

“And I think it’s tailoring something to the individual within a parameter. And I think that’s what’s happening here, it’s not just one prescription fits all.” [Patient 1, 52 years old female]

“He [health professional] sort of like focused on my scoliosis in my lumbar spine rather than my thoracic issues and my kyphosis, so I pointed that out and he gave me some, not alternatives but alternative ways of actually doing a couple of the exercises, which will be easier for me but should still give me the same benefit. So yes, he was quite helpful.” [Patient 25, 27 years old male]

Several patients also highlighted that a standard self-management programme might not work for all patients with chronic back pain. To improve the focus on a patient’s condition and address his/her problems, they suggested that a greater degree of patients’ involvement in the development of their treatment and care plan was needed as part of a good patient-professional partnership.

“If people [health professionals] met up and discussed it when I was there, emm, I meant that is the better case that it would be great to have those professionals in there. And discussing ok this does work,

and that doesn't work, then see what we can think of.” [Patient 3, 29 years old female]

6.6.2.6 Having continuous care with particular health professionals

As described in Chapter 4, patients referred to the clinic were under the treatment and care provided by several health professionals with different expertise. These health professionals worked as a team and provided the care and support needed at different stages of the treatment process. For example, physiotherapists mainly focused on examining patients' physical movement and advising exercises to strength supporting muscles and health care trainers spent more time in teaching patients Tai Chi, Pilates and other relaxation skills. However, patients commented that it would be easier to build a good partnership if they visited the same health professional throughout the treatment programme and that this would provide continuity of treatment. This also would make the consultation process simpler as patients would not need to describe their condition several times.

“It's good if you can also see the same person as well because you kind of build up a rapport with that person, and that person knows everything.” [Patient 17, 48 years old female]

6.6.3 Barriers to a good patient-professional partnerships

To further understand patients' perceptions of a good patient-professional partnership, they were also asked to identify factors which could impede or had impeded the development of patient-professional partnership based on their experiences in the clinic. These factors included: lacking sufficient information provided by health professionals, lacking of an individualised approach for their treatment, being treated differently from what patients expected, gaining no improvement, and being given insufficient consultation time with health professionals. These barriers have not been listed in any order of priority.

6.6.3.1 Lacking sufficient information provided by health professionals

A number of patients commented that it was difficult for them to feel close to and/or build a good partnership with health professionals when there was insufficient information given by the health professionals. Such information included explanations on their specific back pain, treatment plan and process, each health professional's expertise and background, and how the treatment, support and exercises would benefit them. Patients also provided examples to expound their argument based on their past experiences, most of which happened during the consultation with their GPs. Patients expected health professionals to explain the cause of the pain, helping them understand the reasons why they were in long term pain and the appropriate treatment to ease their symptoms. Patients felt disappointed that they had put so much effort and time into searching for the cause of their pain, but there was not an accurate explanation given by their doctors. Consequently, some patients reported losing patience and trust in their health professionals.

“Here I think I’ve learnt a lot about pain management. But I don’t think I’ve learnt a lot about the source of my pain, why I’m in pain.” [Patient 5, 29 years old female]

“He [GP] didn’t explain anything to me. Somehow I felt he was...he was hiding something, you know, I felt he was... that if... all he had to say was that and it would have been partially okay, but he didn’t, he just... it was like he dismissed me and that made it worse, that’s a downward spiral.” [Patient 1, 52 years old female]

During patients' treatment in the pain clinic, patients suggested that it may be beneficial for them to have a copy of their coherent treatment plan and process created by health professionals. This would enable them to understand what to expect in each session and monitor the progress.

“I had no idea. I had the book but they didn’t really explain what happened in the first sessions. And since then I mean I have been kind of like every session has been flying blind into the next one. So when I came in today I didn’t know what was going to be next.”

[Patient 5, 29 years old female]

In order to seek specific support from each health professional in the clinic, a brief introduction to the background and expertise of each staff member was desired by patients. Then patients could prioritise their health needs according to professionals’ skills, and discuss the plan with their health professionals.

“I think once I’ve seen them all sort of more than once I’ll probably feel a bit better, which is probably why I connected with the other lady because I have seen her twice. So I understand what she can offer me.” [Patient 22, 49 years old female]

Patients also expected to receive relevant information and explanations on how the treatment, support and exercises offered by health professionals could be of benefit to them, instead of being treated as a passive recipient of the treatment of pain management or a series of instructions for exercises.

“Certainly last time she (health professional) explained it so much more, whereas previously it was ‘we’re going to manage... help you manage your pain.’ And of course I was a bit resistant because I think I manage my pain taking painkillers, which works. [Patient 2, 58 years old female]

6.6.3.2 Lacking of an individualised approach for the treatment

To underline the fact that being treated as a person rather than a generic patient would enable a good patient-professional partnership, patients further commented on its importance in the opposite way. That is, the lack of an individual approach for the

treatment would be an obstacle to their partnerships with health professionals. Patients were clearly aware that a standard treatment plan and process could not satisfy each individual patient's needs. For example, some patients preferred to manage their pain by practising physical exercises, others favoured pacing themselves. Several patients emphasised that it was necessary for health professionals to adopt an individualised approach based on their health conditions.

“And it’s what works for one doesn’t always work for everyone else. But sadly, you go to some clinics and they say ‘this is what you do and everyone that goes through that door has to do that one thing’, but it doesn’t work like that.” [Patient 12, 55 years old female]

“They might already have like a preformed opinion; I mean they have to be able to sort of take on board what you’re telling them and work with you on that. And if they don’t do that then that relationship is going to break down very quickly.” [Patient 25, 27 years old female]

As noted above, patients also explored factors that may account for the absence of an individualised approach for the treatment. One aspect, mentioned by almost every patient, was that health professionals showed no interest in listening to and understanding their back pain and personal situations. Therefore it was not surprising that treatment plans created by health professionals may not be well adapted to patients' current lifestyles.

“The lady I’ve just seen today, although very nice, very professional, she was reading off a screen, does not fully know what my circumstances are at home. So in that sense, she doesn’t necessarily know what I’m doing. So it’s a bit hard for me to get on with her.” [Patient 22, 49 years old female]

In some instances, patients felt that although health professionals did listen to them detailing their conditions, they neither ameliorated the treatment plan nor showed more awareness of patients' daily lives afterwards. Patients believed that this would be a barrier to a good patient-professional partnership, unless health professionals listen carefully to their stories, accept the negative impact of pain on their lives, improve treatment processes based on their circumstances, and change the way they behave in the consultation.

"I've had that in the past with like GP's and other doctors. So it's like they have to listen, and if they don't listen and don't take on board what you're actually telling them then yes that would be a block to the relationship, definitely." [Patient 25, 27 years old male]

Not only does the treatment plan have to be individualised, but also the way that health professionals delivered the self-management programmes were preferred to be personalised. Patients commented that it was better to be asked than to be told. This was reflected in some patients' experiences in the clinic, in which health professionals made their suggestions sound like an order to patients when delivering some physical exercises. Therefore it was not surprising that some patients were unwilling to follow the instructions and a few others finally lost their confidence to achieve the goal.

"Whereas he made it sound like I have to push myself through it. It was like 'right, you've got, you have to do 10 of these, you have to do 10 of those, and you've got to do in this way...' and I think that's where I lack...no I'm not gonna do it, I don't want to be in pain." [Patient 11, 45 years old female]

6.6.3.3 Being treated differently from what patients expected

As described above, many patients identified that the absence of an individualised approach for the treatment would impede the development of patient-professional

partnerships. Around one third of the patients linked difficulties in building a good partnership with health professionals to the fact that they were being treated differently from what they expected before their attendance in the clinic. As a result of this, these patients seemed in doubt as to whether or not it was an appropriate referral, and unwilling to have a partnership with health professionals.

“But from my perspective, I would like a litter bit more hands on stuff with the physio, maybe osteopathy, chiropractic, along those lines, I can talk a little bit more about the kind of other issues that I might be experiencing with my particular condition, but as I say, I know it is not the aim of SpineFit, but that’s (hands on treatment) purposely what would help me.” [Patient 3, 29 years old female]

It was interesting to notice that a few patients related their experiences of being treated differently from their expectations, to incorrect or insufficient information obtained from their GPs. In some instances, patients had been improperly referred to this clinic and told by the GP that they would be further referred for a MRI scan. Also, there was a lack of any explanation for the physiotherapy in the clinic from the GP, which was different from the usual physiotherapy that may cover biomechanical assessment of movement, manipulation, and neurodynamic rehabilitation. This may suggest that it is important for the GP to understand both patients’ expectations and what the service specifically can provide in order to reduce inappropriate referrals, inappropriate patients’ expectations, and additional costs for resources.

6.6.3.4 Gaining no benefit or improvement

Patients with a similar or lowered level of self-management ability for chronic back pain at the three months follow-up identified the absence of benefits received from treatment and health professionals’ support as the main barrier to the development of a good patient-professional partnership. Specifically, these patients were critical that

health professionals in this clinic only provided exercise prescription and verbal support and no medical interventions or hands on approach designed to diagnose and treat the pain. To this extent, these patients perceived that gaining no benefit was also closely linked with other factors including “lacking of an individualised approach for the treatment” and “being treated differently from what patients expected”, as patients preferred to be treated within an approach combining both verbal support and physical treatment for chronic back pain.

“It’s more like a talking service. I don’t know. I just don’t really get it at this minute. Maybe things will change, maybe will improve, but at this minute, I have no benefit, I don’t see any benefit.” [Patient 20, 35 years old female]

On the other side, given the fact that patients had suffered from back pain for a long time, they realised that it may be necessary for them to have patience with health professionals and understand that it would take time to make a difference.

“It would be a long slow process, get things back moving again. You can’t even have a deadline; you can’t have a goalpost because you don’t know how your body’s going to respond.” [Patient 2, 58 years old female]

6.6.3.5 Being given insufficient consultation time with health professionals

It was not surprising that patients frequently pointed out the lack of sufficient time spent with health professionals during each session as a barrier to a good patient-professional partnership. This factor became more obvious when patients were with their GPs who only provided 10-15 minutes for each appointment, suggesting that there was no time for them to listen to patients’ stories, understand their health needs and design an individualised approach for treatment. Therefore it was difficult for patients to communicate and build up a proper partnership with health professionals.

Longer appointments were desired by patients in order to let health professionals obtain their full history of pain, medication, other health-related problems and their personal concerns.

“I mean you’re only in 15 minutes. I don’t think you could... it’s not long enough to build up a rapport really with someone.”

Being given limited time also meant that patients received insufficient information from health professionals. Several patients complained that due to the limited time, their GPs just prescribed medications without listening or taking any notice of the signs and symptoms of the pain. It seemed that sending patients home with a pack of medications was the easiest and quickest way to complete an appointment. Consequently, patients expressed concerns over the competency of GPs and that their GP might lack specialised knowledge in the area of chronic back pain management.

“They don’t do anything about your back but give you painkillers really because they haven’t time, and I don’t think they’re always trained to do that are they. And they’ve done their bit at what they can, yes.”

[Patient 4, 54 years old female]

Not only did patients experience insufficient time within each appointment, they were also concerned about the length of the courses of treatment. A number of patients were worried that their pain and other health problems may occur again after being discharged from the clinic, since there was no further support from these health professionals available.

“Well it’s the NHS you only get X amount of appointments and they discharge you. You do feel a little bit like, well am I going to be left high and dry again? And if you end up with no support that’s where

you end up in getting back into that mess because you're in a level of despair. [Patient 5, 29 years old female]

6.6.4 Theme summary

In this theme, patients primarily focused on discussing partnerships between patients and health professionals, from their perspectives. In general, patients commented that it was necessary to build a good partnership with health professionals, in which both patients and professionals were needed to make contributions towards the desired health outcomes. Patients further identified facilitators of and barriers to a good patient-professional partnership based on their experiences. For patients and professionals, having a desirable attitude and being willing to share information and take responsibility for health outcomes may be the first step towards a good patient-professional partnership. For patients with chronic back pain, they expected their health professionals to sit with them, spend time listening to their history of pain, and try to understand their health needs and personal stories as part of a good patient-professional partnership. Moreover, patients highlighted that being treated as a person with an individualised approach, designed especially for their condition and circumstances, and accessing continuous care for pain management would facilitate the development of a good patient-professional partnership. Conversely, patients reported a series of factors which would impede patients from building a good partnership with health professionals, including the absence of sufficient information relating to the pain and its management, and lack of an individualised approach for the treatment. Patient also felt that it would be an obstacle in their partnership with health professionals if they have been referred to an inappropriate service, or treated differently from their expectations. Furthermore, patients expressed concerns over receiving no improvement from the service and being given limited consultation time with professionals, both of which may hinder their partnerships with health professionals.

6.7 Being supported by health professionals in the clinic to cope with the pain

When faced with a difficult journey seeking for support and solutions for years, a new experience focusing on pain management may play a powerful role in influencing patients' perceptions and behaviour on their back pain and other related health problems. One important component identified was how patients perceived the support on self-management of chronic back pain provided by the health professionals with specialised knowledge after having been referred to this clinic. In this theme, patients' journey with pain self-management support was followed, from getting started with the service, through ongoing engagement with information and activities, and finally exploring how patients practised the self-management skills with potential benefit. Discussion of patients' experiences of how they were supported by health professionals in the pain clinic also informed patients' perceptions of the effectiveness of the self-management programmes.

Health professionals' support on self-management was extensively discussed across all the patients. Patients reported that their treatment were underpinned through a partnership, in which health professionals provided self-management support and patients were willing to follow the advice and support of the professionals and practise their exercises. There were five key approaches identified by patients in which health professionals supported them to self-manage their back pain: holding patients accountable for their pain management, supporting through providing useful information, supporting through providing physical exercises, supporting through providing psychological support, and supporting through providing holistic care. Within each approach, patients described resources which were used by health professionals to help them cope with the pain, including toolkits, relaxation CDs, ideas and exercise tips. Patients also reflected how their partnerships with health professionals were influenced by each approach and on their experiences. Each approach was outlined as a category which is explored below in more detail.

6.7.1 Holding patients accountable for their pain management

Many patients described the fact that health professionals helped them prioritise their health problems and set goals on their initial assessment. The importance of goal setting went beyond solely being supported to prioritise health problems for pain management. More importantly, patients described that they were taken notice of and held accountable by health professionals to seek for solutions to manage the pain and to work together towards their goals. For instance, one patient recounted that her physiotherapist in the clinic noticed her swollen fingers straight away and asked how long they had been like this, which was completely outside of the patient's expectation [Patient 7, 68 years old female]. Her physiotherapist further suggested alternative medications with exercises, helping her to improve the swelling and pain.

6.7.1.1 Supporting patients to set goals

An important part of the patients' initial assessment in the clinic was that health professionals helped patients identify the main problems that were important to be addressed for improving their QoL and increasing their confidence to self-manage the pain. These main problems were then followed up and set as goals within the patients' treatment plan created by health professionals in the following sessions. Patients described feeling confident and able to cope with their pain when having goals set up for the short, medium and long term. Patients could use their set goals and treatment plans as references to monitor the progress of their self-management ability.

"I just have to go away and I just have to sort of sit down and make plans. That's what I've been told to do is to make a plan of what's going to be done. If it doesn't have to be done, don't do it." [Patient 23, 28 years old female]

Some patients also considered the process of goal setting as an individualised approach in which health professionals delivered their treatment, based on patients'

current situations. Health professionals' support and suggestions were perceived as being adaptable rather than being strictly adhered to as per their treatment plans.

“So that’s been quite good, and just to change my goals just a little bit to try something a bit different. And something that’s really obvious I’ve not tried. Finally, we came up with the step thing and my partner’s going to do me a step.” [Patient 12, 55 years old female]

6.7.1.2 Helping patients find solutions for their pain and other difficulties

The majority of patients identified that it was very helpful to have health professionals who they could talk to about their challenges in self-management and find solutions to those challenges they experienced in daily life activities. In most instances, patients felt they were struggling to manage their pain, as they lacked specific knowledge on self-management or failed to practise certain exercises due to their poor physical functions. Therefore it was important for patients to have someone professional to troubleshoot and problem-solve as part of the treatment.

“She was helping me with postures and so on, it’s supposed to be physio but it’s not really physio, she’s just going to help me find ways in which I can manage going about how I... like how I sit and posture and everything. So I know I don’t have to be worried that it’s going to be like last time when I had physio, because when I had physio every time I left I was in so much pain, I couldn’t do anything.” [Patient 23, 28 years old female]

Not only did patients feel being helped to find solutions useful, but they also praised the attitudes of health professionals who were willing to help patients. Some patients also made comparisons between health professionals in the clinic and their GPs to illustrate that health professionals in the clinic were willing to talk to them and

troubleshoot with them to find alternative solutions, whereas GPs only provided general suggestions as part of their routine job.

“And it seems like as soon as I get here, they gave me the information, and also they are willing to help. It’s not like some doctor that I met in another hospital; they gave me information cos it’s their job.” [Patient 18, 37 years old female]

Some patients further highlighted that health professionals’ willingness to help patients was also reflected by providing information, discussing their successes and challenges in self-management and being patient with them. These features have been echoed in the facilitators of a good patient-professional partnership, as discussed in the previous theme.

6.7.2 Supporting through providing useful information

Considering the fact that the pain clinic did not provide medical intervention for pain management, information was perceived as an essential resource delivered by health professionals. Such information included explaining chronic back pain to patients, providing information relating to pain management, having a range of accessible materials to support patients’ self-management, and providing reassurance. Most of the patients described that they now had a better and more systematic understanding of their chronic back pain which had not been explained properly by their GPs. Many patients referred to the value of the information in general, and also to individual practices and alternative pain management strategies from which they had gained benefit. Some patients appreciated the reference books given by health professionals, The Pain Toolkit and Pain Management Plan, in which a set of skills, strategies and other patients’ experiences enabled the patients to feel equipped to self-manage their condition and lives as a whole. Having had a thorough explanation about chronic back pain and offered a range of pain management strategies, a number of patients who

used to worry about the life-threatening risk of losing control, for example, whether they could have sat on the wheelchair because of the pain, pointed out that information from health professionals was perceived as reassurance, increasing their confidence to cope with the pain.

6.7.2.1 Explaining: helping patients understand their pain

Around half of the patients described that their experiences in the pain clinic enabled them to have a good understanding of their chronic back pain. From patients' experiences, having a clear understanding of the cause of the pain was considered as the basis and evidence of pain management. It also enabled patients to build up their confidence and belief in self-management. Several patients described that a lack of an explanation of their specific condition would result in their reluctance to cope with pain through self-management.

“Certainly last time she [health professional] explained it so much more, whereas previously it was, we’re going to manage... help you manage your pain. And of course I was a bit resistant because that wasn’t what I wanted. I mean I think I manage my pain taking painkillers.” [Patient 2, 58 years old female]

“She [health professional] seems very nice and she explains everything and shows me how to do it and... and I can see immediately that I have done things wrong in the past, and yes, it’s helping an awful lot to be honest.” [Patient 4, 54 years old female]

Providing explanations about their conditions to patients also contributed to the partnership being established between health professionals and patients. Patients often sought the cause of the pain and preferred to have a specific diagnosis before they were convinced to accept the nature of their condition and adhere to the treatment and self-management plan. Therefore it was perceived as a downward

spiral when there was a lack of an explanation of their pain provided, particularly no clear diagnosis after having undergone all necessary investigations.

“When you know you’re in pain, you know you can’t walk, you’re rolling around on the floor, but someone is telling you, a professional, a doctor who studied for years and years and years, is telling you there’s nothing wrong with you. Somebody else’s doctor may be perfectly wonderful, but my doctor was not about this, about this spine thing, he was not good.” [Patient 1, 52 years old female]

Sufficient information and explanations about patients’ specific pain could also help both patients and health professionals seek accurate approaches to address their problems. With the information, they could take further actions to explore the most appropriate treatment, medications and management strategies.

“She’s helped me try and understand why I’ve been getting like pins and needles in my arm. So she’s given me a possible name of what it could be and I just have to go back to the doctor and speak to him. So I’ve been given quite a few resources that I can go to if I need to.” [Patient 23, 28 years old female]

6.7.2.2 Providing information relating to self-management

The aim of the pain clinic was to help patients self-manage their chronic pain by providing support and suggestions, by health professionals primarily focusing on the delivery of information on the self-management of chronic back pain. Such information included the advice given specifically on patients’ current medications, alternative treatment, and self-management skills and tools. Nineteen out of the 26 patients perceived the information as being fresh and helpful to manage their condition and lives.

“Now, obviously talking to the SpineFit group, it’s a little gentle exercise, walking, keeping active, because you don’t realise, and this is something that I have learnt. This is something that everybody needs; it’s all about the information.” [Patient 11, 45 years old female]

Having understood the cause of the pain and the skills related to self-management, patients gradually accepted their long term back pain and realised the importance of undertaking exercises for self-management.

“I’m realising that instead of getting in a state about having pain, which I should really just stop and relax and relax my muscles; my muscle structure can be a very bad problem for me and if my muscles get too tense I can’t move again.” [Patient 4, 54 years old female]

Meanwhile, patients’ confidence to actively cope with their condition and maintain their normal life could be increased by having access to sufficient information, particularly about the successes and potential challenges of self-management practice.

“I’m still carrying on my life, I don’t have to halt my life, I can go sideways, I can go, you know, off at a tangent if needs be, and that’s supported by the things that I’m learning here.” [Patient 1, 52 years old female]

6.7.2.3 Having a range of accessible materials to support pain management

Not only did health professionals in the clinic provide information relating to pain management for patients, but they also offered them the written materials referring to a variety of general pain management tools, for example, pacing, prioritising and planning daily life, relaxation, and a sleeping CD. This provided the freedom to choose what was appropriate to their personal needs, rather than having to adhere to a fixed or standard self-management programme. In addition, there was a list of websites attached to the materials where patients could look for more information relating to

chronic pain. Patients described how they used these materials to help them set up goals in the short, and medium to long term. This gave a sense of having the resources to manage the pain at different times of day and in different situations. Meanwhile, patients commented that the materials were easy to understand and remember with the use of cartoons and pictures.

“It’s easier to read because it’s much bigger, but it’s just... it seemed to be more... it’s more detailed. But the previous ones [materials given by other service] were very much, this is what you’ve got to do, rather than why don’t you try this. So this one suggests rather than tells, and it’s always better to be asked than to be told.” [Patient 22, 49 years old female]

Although these materials were perceived as being useful by most of the patients, a couple of them pointed out that the information and strategies were too general to meet their needs, and suggested that there should be more in-depth information and a higher level of detail available to satisfy patients with different needs in regards to both their health circumstances and the level and complexity of information they would like.

6.7.2.4 Providing reassurance

Patients reported that having both sufficient information and verbal explanations from the health professionals provided reassurance and reduced their fear and worries about self-managing pain. Some patients had had previous experiences of managing their conditions by practising exercises, stretching and massaging, but they were not fully confident about the consequences, as there was a lack of a mechanism explaining how these actions could benefit their condition. Therefore patients could be reassured and gain confidence from the information provided by health professionals in the pain clinic, to be willing to self-manage their pain.

“But I’ve just checked it with him (health professional) and he was quite surprised because he asked me to do something and I went beyond it, and he said ‘oh...’ I said I’ve been doing this and he was really happy with it. So it just reassures what I’m doing is correct, and I don’t want to be doing something that is not appropriate for me. So it’s good in that aspect, yes.” [Patient 9, 43 years old male]

“Like I was worried about the spine, I was worried about the disc coming out; I spoke to her (health professional) about it, she showed me a spine that they have next door, and she said, this is the situation, it can’t come out. It can slip, it can move, but it can’t come out because it’s trapped between two bones. So I don’t worry anymore.” [Patient 21, 69 years old male]

6.7.3 Supporting through providing physical exercises

In addition to information delivery, health professionals in the pain clinic taught physical exercises to patients which provided a practical way to manage their chronic back pain. This sub-theme illustrates how these physical exercises and skills influenced patients’ sense of being supported by health professionals to cope with the pain.

Patients reported that health professionals in the clinics often suggested a set of easy and gentle exercises to them after the first couple of treatment sessions and demonstrated the exercises in person. Before patients left the clinic, health professionals also printed out the exercise instructions for patients to practise at home. This was strongly represented in the data with positive feedback provided by patients. For most of the patients, it was a new and different experience to manage their pain. Patients also described the fact that doing these physical exercises could result in

more pain for a short period of time, however they realised that this pain would not cause any harm and may benefit their condition and lives in the long term.

6.7.3.1 Suggesting exercises to patients

For most of the patients, it was not a completely new experience to be introduced to physical exercises to manage their pain. However compared to their previous experiences in learning and practising exercises, patients highly valued the simplicity of the exercises given by the pain clinic, which were easy to remember and practise in any situation.

“So yes, it’s stuff like that that stays in my mind. I’ve got to be honest, the exercises I used to do when I was doing physio originally, I can’t even think of them, they’re gone for some reason, I can’t remember them. But the ones that she (health professional) taught me, they’re there (in my brain) and they’ve stayed there and I do them when it starts.” [Patient 19, 44 years old female]

When being introduced to a range of gentle exercises, it was also explained to patients by health professionals in the clinic how they would benefit from them. This was particularly apparent in patients’ discussions, when comparing their previous experiences in which they could not understand the rationale of practising exercises given by GPs or other professionals. This increased patients’ willingness to adhere to or engage in practising physical exercises.

“I went to Pilates before, I always force myself, like it’s pain, but it’s ok, it may be better, cos the instructor didn’t tell me anything. So that’s what happened, that’s why I don’t work anymore. But now I know why I am doing what I am doing. And I feel much more confident as well.” [Patient 18, 37 years old female]

6.7.3.2 Guiding patients in doing exercises

Different from other services which patients had experienced, patients described that health professionals in the pain clinic demonstrated exercises in person to them when teaching and explaining to them about the physical exercises. This clearly contributed to patients' sense of being supported to self-manage the pain. In addition, showing patients how to practise the exercises was positively perceived by patients in terms of facilitating the relationships between patients and health professionals.

"They have also demonstrated well, what I have to do, which does make a big difference. Rather than they putting me on the bench, and say 'right, this, that and that.' To have it demonstrated, so I can look on, and I think this is very good." [Patient 7, 68 years old female]

Many patients further commented that health professionals in the pain clinic not only demonstrated the exercises to them at the beginning, but also reviewed the way in which patients practised them in the follow-up sessions. This was also considered by patients as an encouragement to have their treatment progress regularly checked by health professionals.

"She showed me and actually asked me to do the exercises while she was there to make sure I'm doing them right to make progress. I think it was really good motivation." [Patient 26, 63 years old female]

6.7.3.3 Willing to practise exercises

For some patients who had had prior experiences of practising exercises, it gave them familiarity with fundamentals of self-management in the pain clinic. Patients who had not engaged in exercises described that they were willing to learn and try every new thing.

"I try and do something every day. It's more of a hybrid as I've seen so many physios and so many... yes, overwhelming with information."

I try and do something every day, even if it's just, just to go for a walk. So some of them have just become part of my day." [Patient 5, 29 years old female]

In addition, by providing written materials with no strict requirement on the amount of exercise taken daily, patients took control of the exercises themselves and adapted practices to their needs. This also contributed to their attitudes and willingness to practise exercises provided by health professionals in the clinic.

"Because of the Pilates, you know, that SpineFit gave to me, so I can now do these exercises at home whenever I want, then I will feel better. Even when it's snowing or bad rain, I can still do it at home. I don't have to have the stress about it (going to a class)." [Patient 18, 37 years old female]

Although it was not expected that practising exercises would lead to an immediate positive impact on patients' pain status, some patients observed changes in their experiences with practising the exercises. These changes were seen as a great drive to continue their practice.

"The exercises I've only been doing for about four weeks, yes. I was doing the relaxation before that, but I have noticed that the exercises are making really an immediate difference I'd say. Yes, I can really feel some of them when I've done them (laughs), so they're building up muscles in the correct place." [Patient 4, 54 years old female]

6.7.3.4 Realising the fact that pain will not cause harm

It was generally not a pleasant experience to start practising physical exercises for patients suffering from back pain for a long time. Nearly half of the patients recalled particular challenges with their exercises, some of which caused more pain or discomfort when stretching their muscles and bodies.

“When I was originally given exercise to do physio, it was so painful that I couldn’t do it. So the only exercise I can do is... you see I haven’t even tried swimming because I’m scared that I can’t do it. But I do walking.” [Patient 23, 28 years old female]

Notably, all of these patients had continued to engage with exercises, either building up their exercises on a daily basis or choosing alternative exercises to meet their needs, despite these difficulties. Patients further explained that they were aware of these challenges because of the detailed explanations and examples of others given to them by health professionals in the clinic, informing patients that this might happen at the beginning. This pre-notification produced reassurance and enhanced trust in the health professionals, which supported patients in remaining committed to practising exercises.

“Honestly I felt my injury... I thought by me doing this exercise I’m injured so why is he (health professional) asking me to do this, because it’s making it worse. But in hindsight in looking at it, I felt pain at the beginning, but that pain has made me recover from my injury. If I’d not had that pain I wouldn’t have been able to recover.” [Patient 9, 43 years old male]

6.7.4 Supporting through providing psychological support: helping with stress and depression

As was discussed in 6.4.1.3, chronic back pain could bring about a negative impact on patients’ emotions, leading to stress and depression. Many patients agreed that *“depression obviously plays a huge part in pain” [Patient 1, 52 years old female]*. A number of patients commented that in addition to physical exercises, they were supported psychologically by health professionals in the clinic. Although some patients still had a similar level of pain after their attendance in the clinic, their

experiences in the clinic and interactions with health professionals made them more positive and optimistic about their condition and lives, which enabled them to relax and let go of some of their anxieties. Patients could feel and identify positive changes in their mind and mood, producing benefits which included sleeping well, not feeling isolated, relaxing the muscles and being able to concentrate. These positive changes also improved their anxiety and depression status, with greater confidence to manage the challenges they faced.

“We don’t just discuss my pain or the exercises, it’s all of it, my depression, everything really. It’s the best for somebody like me, who is having an emotional mental health problem and has physical pain problem as well. You know, it’s what’s needed.” [Patient 11, 45 years old female]

Patients also highlighted the useful resources relating to psychological support provided by health professionals, including meditation, relaxation CD, and breathing techniques. Some felt the connection between chronic back pain and suffering from low mood and stress, and realised that their pain experience could be reduced by improving their mental health status.

“I think they (health professionals) probably improved my sort of relaxation, because I think my lower back, a lot of it is now quite muscular, despite the fact that I’m just tense because I’ve been uncomfortable for so long. And I think it probably helps with the muscular side of just chilling and relaxing a little bit. As for whether it’s helped with my disc going back in, you know, I don’t think anything will (laugh). So I think it’s more about... it is more about coping with the pain than it is about resolving the source of pain at the moment.” [Patient 5, 29 years old female]

This greater awareness and understanding of the associations between their condition and the psychological impact also provided patients with greater confidence and competence in self-managing their conditions. This is further explored in detail in 6.9.3.

6.7.5 Supporting through providing holistic care

In comparison with the primary care service that patients received from their GPs, about two thirds of the patients remarked that the pain clinic offered a more holistic care and a team approach towards pain management. In addition to support and advice given on their pain management, patients also received attention and care for their overall health status. This combination of providing support on both pain management and other aspects of health care formed the basis of the holistic care approach in this clinic, with the potential benefit of increasing patient satisfaction.

Patients referred to this clinic generally had experienced a poor QoL; however their journey in the clinic changed their life style with the skills learnt from health professionals. Meanwhile, self-reported improvements in patients' general health and other aspects of life, including eating habits, sleep pattern, emotional health, social activities, job management, and financial difficulties, were attributed to as part of their treatment process. Whenever needed, patients were also referred to other relevant services. Patients described that they received a great degree of unexpected help and support from health professionals in the clinic.

6.7.5.1 Being supported to change life style: pacing

Pacing was an important management skill taught by health professionals in the clinic, enabling patients with chronic back pain to undertake activities one bite at a time and not to tackle all of them at once. As part of this process, patients also learned how to plan and prioritise their workload. Most of the female patients regarded it as a particularly useful skill to help them manage the home and housework.

“I am more active now. I can plan more things to do. So generally, that is better. And just, well it sounds silly, but get up and doing a little job every evening, instead of that long list, so doing little by little, that does help.” [Patient 7, 68 years old female]

“I try not to do many things in one day, if you know what I mean. Like if I plan to meet my friend, then I do shopping on the other day. I’d better keep to one thing at a time. I just get used to it really.” [Patient 20, 35 years old female]

Practising pacing also allowed patients to build up their pain management progress and patience. Rather than carrying out multiple tasks at once which may result in being inactive and losing fitness, patients tried to take a break and carry on in a flexible way. This also helped patients recognise their early warning signs and symptoms before experiencing escalating pain, producing a sense of safety in which patients could take control of their pain.

“Last week, I went out doing the garden, mowing lawn, but I wouldn’t rush it if you know what I mean. I cut half of it, and saying I’m gonna do that tomorrow. So I keep myself at the level when I know: one I won’t cause myself more pain, and two I’m not going to ring the pain on by doing it.” [Patient 14, 57 years old male]

The concept and skills of pacing had a very positive impact on some patients, enabling them to appreciate themselves and create kindness to their bodies. Because of their chronic pain, patients’ incapacity and struggles had reinforced their negative and self-critical thinking, and some of them even blamed themselves or felt guilty for their pain difficulties and the situation they were in. These negative judgements considerably affected the way in which patients dealt with their pain, creating anger, anxiety and depression. In this instance, pacing provided them with an opportunity to pursue and achieve their goals in life step by step, with the benefit of increasing their

confidence and self-esteem. Reflecting on the shift from blaming to appreciating in the process of pacing, patients discovered more what they were able to do, rather than focusing on what was not possible. These changes influenced their behaviour towards pain management, and they felt more satisfied and realised the value of looking after their bodies.

“I have... I have found a difference in managing it myself and putting myself first. Like for instance four weeks ago I got out of bed and I’ve gone to move and I thought, oh I can’t move. And straight away instantly I’m phoning in sick. But I wouldn’t have done that at one point. They’ve taught me to think about yourself a lot more, put yourself first. So I thought I need to be fit, I need to be right for me. And I phoned in sick, didn’t bat an eyelid and I’ve got better, a couple of days rest.”

Patients also described the positive influence of pacing on their emotional health status. Making a list of things to do, slowing down and putting themselves first allowed them to live their lives under less pressure. This was also perceived as an important facilitator to reduce their anxiety and stress, enabling patients to reflect on their past experiences in pain management and believe that it was not the pain itself that impeded what they could achieve.

“So that (pacing) is what I started doing, because as time goes by, and I found that I managed it a lot quicker and better, I managed to put everything in now, and they got done. So pain can’t stop me doing anything now!” [Patient 13, 56 years old female]

6.7.5.2 Seeing the whole picture of the patient: helping with other problems

About half of the patients discussed their experiences of being supported with other problems in life by health professionals in the clinic. In contrast to visiting their GPs

who primarily focused on only one of their symptoms within each appointment, patients described that the pain clinic offered a holistic care approach concerning not only pain management, but also other issues relating to QoL, for example, weight control, sleep pattern, job management and family events.

“We did not just spoke about my pain today, it’s been about my eating habit, about my sleep pattern, and all of that. It’s... everything that could be, what’s the word? Holistic care, is what I get from here, it’s not just, right, you are in pain, this is what you need to do. It’s holistic, which is brilliant, it’s what’s needed.” [Patient 11, 45 years old female]

Although patients felt easier into building a good partnership with the same health professionals, some of them also valued the importance of having a team composed of a number of health professionals in the clinic, providing different support and solutions based on each one’s expertise. The combination of information, knowledge and skills offered by different health professionals consolidated the foundation of holistic care.

“It’s not just one stop centre for pain. It can... if I was having difficulty socially that would be addressed; if I was having difficulty in other ways, that would be addressed. But it’s not just the one professional with all the information but somebody’s quite happy to say to me, well I’ll refer you to another of my colleagues.” [Patient 1, 52 years old female]

6.7.6 Theme summary

Patients’ experiences in the pain clinic enabled them to feel supported by health professionals and more equipped to manage their condition in a variety of ways. Patients managed to set achievable goals and have problems addressed with the support from health professionals, increasing their confidence in practising self-

management skills. Meanwhile, they had a range of tools available, including written materials about self-management tools, exercises, and new information offered by health professionals, enabling them to experience new ways of understanding and talking about their chronic back pain. With this support and information, patients felt more able to choose appropriate management tools to meet their needs, rather than having to follow a standard programme which risks adding to their suffering. In comparison with treatment and service received from their GPs, patients were offered a more holistic care approach in the clinic, where patients learned how to pace themselves and adopt a new lifestyle living with their pain. This positive inspiration was particularly valued by patients, with the benefit of feeling less worried and stressed about difficulties in their lives.

Being supported by health professionals in the pain clinic was the essential part of their treatment, enabling patients to understand and further manage their health and other challenges in a more feasible way. This may also lead to a change of their perception of and behaviour in self-management, which will now be explored.

6.8 Thinking differently about their chronic back pain

The tools, information and support identified in the previous theme equipped patients to manage the challenges of their back pain and life. This resulted in them having a different perception of the pain and the concept of self-management. Patients' experiences in the pain clinic enabled them to shift their focus from concentrating on and worrying about the difficulties in life to learning and adapting a new lifestyle towards an improved QoL living with the pain. As part of this process, they realised and accepted the nature of chronic back pain, and also reflected on their prior pain management experiences, both of which led them to attempt to cope with their pain using the self-management tools provided in the clinic. Meanwhile, understanding the nature of this pain clinic, patients acknowledged and valued the positive influence of

their partnerships with health professionals who supported them going through the challenges, on their development journey of self-management ability.

6.8.1 Facing the reality and accepting the long term pain

The connection between acceptance, responsiveness and appropriate action was frequently identified by patients. Although some of the patients pursued a cure after being referred to this clinic, it seemed that the explanations, information and knowledge offered by health professionals gradually influenced patients' perceptions of their pain. Patients started to believe that acceptance of the nature of their chronic back pain may be the first step towards self-management, enabling them to lead a better QoL. It also had an important role in facilitating patients' changes in behaviour, allowing them to respond more readily to what was actually happening in reality.

“The toolkit and the pain management is where the focus has been and that’s what I needed really because, you know, it is what it is, it’s not going to disappear anytime soon. So I need to adjust... it’s about managing what’s there.” [Patient 5, 29 years old female]

Facing up to the reality and accepting their long term pain were also important factors serving to build up patients' confidence and capacity for self-management. Rather than being restricted by pain and other difficulties, it gave them more inspiration to take action and control of their pain.

“I’m going to be able to understand my pain and I’ll be able to accept my pain and manage it in the long run, I’m going to be able to manage my pain, and just accept it’s going to be there and not just to disregard it.” [Patient 23, 28 years old female]

“I understand it, yes, it’s never going to get better, but I also understand that I can have these tablets strengthened when it goes wrong, because I have read about these know and that can be done,

which is good. Instead of just being left, it gives you more confidence, more hope in the future.” [Patient 7, 68 years old female]

6.8.2 Reflecting pain management on past experiences

The change in patients’ perceptions and behaviour towards self-management was also reflected by patients’ discussion and review of their past experiences in coping with the pain. This process enabled them to acknowledge and identify the areas where they needed to correct or still had room to grow their self-management ability, encouraging them to attempt to practise self-management. For other patients who started making progress during the pain clinic, this experience provided them with an opportunity to believe and value the change from being in constant pain and doing nothing, to being able to achieve a couple of activities and enjoying their lives more. Patients often described a sense of feeling surprised by seeing a difference in the way of thinking about and/or managing of their pain.

“So I have learnt something from that (relaxation CD), because before I would have said, oh I won’t be able to sit still. But you can sit still if you try. And sometimes your mind does wander but you’ve just got to try and get back to listen to it, I’ve found that helps.” [Patient 8, 49 years old female]

6.8.3 Attempting to cope with the pain

Acknowledgement and acceptance of the reality and the nature of their condition drove many patients to move on from where they were stuck and attempt to proactively manage the pain. Patients’ willingness and interest in pain management were particularly influenced by the use of self-management tools provided in the written materials and exercises suggested by health professionals. Moreover, health professionals in the clinic offered a more individualised programme that could fit in with patients’ different lifestyles and meet their needs. Patients also commented that

the way the health professionals delivered these exercises were encouraging and friendly.

“I mean I have got to be willing to come here and be open to what she is gonna offer, or what SpineFit is gonna offer. I mean I got to go home then go “right, so ok, she (health professional) suggested this, this and this, let’s have a go”. I have got to be open, to do that as well.” [Patient 11, 45 years old female]

Some patients who described how they decided to start managing their pain and doing the exercises also reported that they felt that they were held accountable by their health professionals. Instead of worrying about the potential challenges and uncertainty about the effects of the exercises, explanations of how the exercises could help with the pain were provided as well as reassurance that pain would not cause extra harm.

“So once I’ve tried it, and I may see some... I may find I’m even worse than I was before, but you know, I’ve got to give it a go to see and if it doesn’t work it doesn’t work, we’ll have to try something else.” [Patient 22, 49 years old female]

6.8.4 Understanding the influences of patient-professional partnerships on self-management

Despite the fact that the pain clinic did not offer any medical intervention for pain relief, patients appreciated the effort and support provided by health professionals, which contributed significantly to a change in their perspectives and behaviour of pain management. Patients frequently described that their treatment seemed to be carried out through a partnership, in which health professionals provided necessary support and skills and where patients needed to follow and practise in order to develop and improve their self-management ability for chronic back pain. Almost every patient

recognised the positive impact of such a partnership on their pain management ability development and QoL, including being able to be more active, more informed about their condition, reducing stress and anxiety, and suffering from less pain. Only one patient commented that there was no partnership between her and the health professionals in the clinic, as she already had had a number of years' experience in self-management, and knew and tried everything that health professionals suggested. It seemed that she could not receive any alternative skills from the pain clinic, leaving her in the situation where she felt no difference or progress.

6.8.4.1 Acknowledging the potential influences

As was discussed earlier in this theme, a number of patients noted how their experiences in the clinic and the health professionals' suggestions enabled them to view their negative, self-critical thoughts in the past, and attempt to cope with the pain themselves. Reflecting on their treatment session in the clinic, they also came to realise that the changes in their perceptions were largely influenced by their interactions with health professionals. Although some of the patients had not noticed any reduction in the level of the pain, their communication and relationship with health professionals built up their sense of being supported and cared for. Patients again highlighted the facilitators of a good patient-professional partnership (see 6.6.2), and further explained how these factors enabled them to seek more useful information, conduct more open conversations, build trust in health professionals, increase their confidence and continue their treatment. This acted as a powerful motivation encouraging them to learn self-management of chronic back pain.

“I would agree with that (having a good partnership with health professionals would have a positive impact on my self-management ability). Because I think if you feel that it's like a two-way street, then you feel a bit more involved... I haven't sort of received any of the benefits, but I'm happy in that they listen to me and they'll continue

trying to like help me. I think it's definitely beneficial for like the patient side." [Patient 25, 27 years old male]

6.8.4.2 Seeing that a good partnership with health professionals would facilitate the self-management of chronic back pain

More than three quarters of the patients admitted that they had gained benefit from the experience in the pain clinic, particularly on the development of self-management ability for their pain. These patients highly appreciated the partnerships established between them and the health professionals in the clinic, which enabled the patients to identify a close connection linking the benefit received with the support given by health professionals.

"Well I don't think that we have anything productive happen unless you've got a comfortable partnership where you feel relaxed with somebody." [Patient 2, 58 years old female]

"I'm managing with the walking that I do with the exercises that they gave to me, so yeah, coming here and being given those exercises, here I am actually now managing my pain better than I was before, and that definitely, you know, that came from the partnership of SpineFit." [Patient 11, 45 years old female]

Patients perceived their partnerships with health professionals as an emotional connection, in which they could share their stories with health professionals who were prepared to listen first and willing to provide help and suggest solutions afterwards.

"If you kind of... you appreciate... I just think it makes it more accessible, it definitely makes it more accessible if you've got somebody that you can communicate with and talk to and share with you know." [Patient 2, 58 years old female]

Not only did it provide a platform for smooth communication between patients and health professionals, but also acted as a backup or safeguard to prevent patients from deterioration. Patients described that they felt safe when there was a good partnership built up with their health professionals.

“It’s increased it (self-management) greatly for me because it’s given me the confidence to know that I’ve got the backup there if I need it.”
[Patient 15, 49 years old female]

“So yes I’d say all in all I was doing a lot better. And I think once you understand things as well, what I’m doing wrong, you feel better about it as well because you know you can correct that, they will help you to correct that.” *[Patient 4, 54 years old female]*

A good partnership was also perceived as a great advantage in developing individualised treatment or care programmes in the clinic. Health professionals could gather more facts and details about patients’ condition and difficulties, while in turn patients could obtain more information and knowledge specifically relating to their health needs.

“It’s working for me, but I can see... for me, myself, personally it is working for me. But I don’t think it will work for everybody.” *[Patient 26, 63 years old female]*

“I can manage the pain now; I know exactly what to do; I know how to overcome it, and I know how to deal with it, so it’s taken an awful lot of worry from my side.” *[Patient 21, 69 years old male]*

While patients remarked on the positive impact of having a good partnership with health professionals on their self-management of chronic back pain, it is worth noting that some patients also specified the criteria for patients who may benefit from a pain management clinic of this kind.

“I think it’s very good. I think you’ve got to... I think the service in itself is very good but I think you have to be a determined person and you want to achieve something from it. Whereas I think some people can be quite... I don’t know what the right word is, I shouldn’t say lazy, some people want an instant cure, and I realise that that’s not going to happen, that I have to put as much effort in as they do in this partnership.” [Patient 26, 63 years old female]

6.8.5 Theme summary

In this theme, patients frequently described how their perception of self-management was changed through the supportive approaches provided by health professionals. Patients widely recognised that the acceptance of their chronic condition was a necessary attitude which may increase their willingness to self-manage, leading to a change of in their behaviour. With sufficient information, explanations and motivation provided by health professionals, most of the patients expressed their attempts to practise self-management skills and tools. Through this process, some of the patients also viewed their past experiences and identified the area and priority that they particular needed to work on.

Patients reflected the changes in their perceptions based on their experiences in the clinic, enabling them to realise the influence of having a good patient-professional partnership on the development of their self-management ability. For patients who had not felt any benefit from the clinic, most of them acknowledged the potential positive impact of their partnerships with health professionals, which could benefit their ability for pain management. All patients who had received either emotional or physical benefit not only identified, but also appreciated the connection that the development of their self-management ability was associated with good partnerships established with their health professionals.

6.9 Experiencing a change

Previous themes have identified patients' experiences of living with pain before attendance in the clinic, support received from the health professionals after attendance, and how patients viewed their experience differently and lived differently as a result of practising self-management skills. This final theme focuses on identifying changes or differences in patients' psychological and physical functioning which patients had experienced in their condition and lives, and the impacts of these changes.

6.9.1 Feeling positive about the mindset

The overwhelming majority of patients identified the positive impact on their psychological status as a key benefit they had gained from their experiences in the clinic. They became more positive and optimistic about their condition and lives, with greater confidence and competence to manage the challenges they faced. Patients attributed this new mindset to being supported by health professionals, practising self-management skills, staying calm, relaxing and being positive. Some patients, particularly those who had felt improvement in their physical pain status, also reflected how their mindset had gradually changed their perceptions and influenced them to attempt and practise self-management skills.

6.9.1.1 Gaining confidence and competence in managing the pain

Patients described the service, care, and self-management skills received from health professionals, as well as the partnerships established which helped them to regain their confidence in self-management of chronic back pain. In addition, some patients who used to be pessimistic no longer blamed themselves for living with this condition, using the encouragement and resources provided by health professionals in the clinic. Instead, they believed that there was hope and support available in managing the pain and pursuing a better QoL.

“Yes, I feel confidence in... well is it an illness or a condition. Yes I’ve a lot more confidence in my condition that I can get back to doing something, even if it’s just living a normal life again.” [Patient 4, 54 years old female]

Not only did their confidence increase in managing their condition, patients also described how their partnerships with health professionals had influenced their mindset, enabling them to be positive, optimistic and confident. Relevant information and knowledge about pain and its self-management learnt from health professionals gave patients grounded insight into their condition, which also contributed to their increased confidence and competence in managing the pain and other difficulties in life. Meanwhile, with the benefits gained from practising self-management skills, patients also built up their belief and confidence in the health professionals. It seemed a positive cycle of psychological benefit gained from health professionals, who could potentially influence patients’ mindset that inspired them to pursue further benefit with regard to their physical functioning.

“It’s just having confidence; she’s given me a lot of confidence. And I think because she’s got the confidence in me then I feel like I should... (cooperate to manage my pain)” [Patient 24, 60 years old female]

6.9.1.2 Identifying benefits for emotional health

Unsurprisingly, patients who described differences in their mindset identified positive changes in their emotional health, including being less worried and stressed, and more motivated and relaxed. Patients also reflected on the link between their emotional health with a range of factors based on their experiences, such as information, support and their mindset that could contribute to the increase in their

confidence and competence in coping with their condition. Consequently, their anxiety and depression symptoms could be improved.

“I think it naturally lifted when you know that it’s not the end, when you know that... when you can see a light at the end of the tunnel, I think your mood naturally lifts, the depression the pain causes, it’s still there, but once again it’s managing that.” [Patient 1, 52 years old female]

6.9.2 Making progress on self-management

Patients noted that the service received in the pain clinic supported them in developing a deeper knowledge of pain management and a better ability to cope with their condition, enabling them to feel the progress made in self-management. This reported progress included seeing symptoms improve or stabilise, taking less medication, and being able to keep track of early symptoms and warning signs. This was unsurprising considering that the clinic focused on managing chronic back pain, and the supportive approaches that health professionals took, potentially influenced fundamental patterns of patients’ perceptions and behaviour. However, the degree of benefits that they gained varied, reflecting their particular needs and the practices they adopted in response.

6.9.2.1 Seeing symptoms improve or stabilise

A number of patients remarked that some symptoms were significantly relieved after their attendance in the pain clinic. The most clearly observed changes were the pain intensity and the frequency of pain. Some patients found that they experienced less pain than before, while others realised that the occurrence of pain episodes was less frequent. There were also a few patients who experienced such a significantly positive change that they were able to feel no pain for a short period of time. Although self-management skills were not promoted as a solution for curing chronic pain, these

patients' experience provided support for the case that the practice of self-management could facilitate the improvement of pain experience.

*"The pain is not immediately gone, it takes time but it's much shorter than before. It's not like months anymore, it now comes like weeks."
[Patient 18, 37 years old female]*

"Now I've got... for the last three months I've had no pain and when he (health professional) asked me to do it (bending down) I went straight down, brilliant!" [Patient 9, 43 years old male]

Although most patients expressed such positive experiences, a few of them made further suggestions based on the current situation of this pain clinic and patients' perspectives, in order to shorten the period of treatment time. A frequently proposed idea was the combination of such a pain clinic with other external support. For instance, patients suggested that it would be beneficial to them if they could access other secondary care for back pain (e.g. hands on physiotherapy) simultaneously to when they visited this clinic.

6.9.2.2 Taking less medication for pain relief

Another positive change that patients frequently discussed was the medication used for their pain. Having been provided with information and suggestions about pain medication by health professionals, patients reported that they took less but more effective medication, helping them control pain episodes when necessary. This was perceived as a great help by patients particularly those who suffered from the side effects of those medications.

"It's getting better and better, getting back to normal. I still take the medicine for my gastro but I don't need to take any medicine for the pain." [Patient 18, 37 years old female]

For a small number of patients, they gained considerable benefit and experienced significant changes in their pain intensity. This led them to a direct reduction in their use of medication for pain relief.

“I am not taking my Codeine now. If I’m ever in a really big flare up, then yes, I may take some. But I’m managing with the walking that I do, with the exercises that they gave to me.” [Patient 11, 45 years old female]

6.9.2.3 Being able to keep track of symptoms and early warning signs

While patients experienced an improvement in pain experience, they also changed their attitudes and increased their awareness of pain management. Rather than taking no action, patients discussed how the self-management skills and pacing helped develop their ability to be able to identify the early warning signs of the pain episode and adopt preventive strategies in order to control the pain at an early stage. Such ability has also had a positive impact on patients’ psychological status. Being conscious of the occurrence of rapid worsening pain enabled them to feel less stressed and panicky about taking action to cope with the pain.

“I think I’m having more awareness, you know, awareness of what I’m doing. It’s helping me focus more on the relaxation and the benefit of it.” [Patient 2, 58 years old female]

Some patients also described learning to recognise how certain behaviour would contribute to their condition, and further discussed the close connection between being kind to themselves and paying more attention to increasing their awareness and identifying the signal. Instead of carrying on what they were doing which aggravated the pain, for example, walking or cleaning the floor, they took a break and practised pacing skills to relax, helping to reverse this experience and create a positive cycle of benefit.

“Put myself first and think about myself. And as soon as my pain starts, as soon as I start it feeling a twinge, and then if I... I now know if I push myself it’s going to go and I’m going to be off work. And now if I get that twinge I take a step back and think, wait a minute, what am I going to do that’s going to aggravate that, and not do it. I think about it a lot more than what I used to do.” [Patient 19, 44 years old female]

6.9.3 Finding it possible to lead a normal life

Over half of the patients shared their experiences of feeling less stressed in life, and finding it possible to adopt a more balanced lifestyle. They identified how their increased awareness and self-management skills learnt from the clinic enabled them to minimise the effect of other pain-related problems, leading to a better QoL. This change was particularly advocated by those patients who had achieved certain activities that could not be managed before in their routine lives, for example, managing some housework, enjoying social activities and traveling. They realised that the self-management techniques provided by the clinic shrank their experiences of pain and other problems while expanding a new experience of gaining benefit and living a normal life. Meanwhile, these changes also encouraged patients to look forward to their lives in the future.

6.9.3.1 Coping better with other pain-related problems

Patients described the improvement of their ability to cope with other difficulties and problems caused by their chronic pain. They noticed changes in a number of symptoms, including sleep, walking and doing housework, as a result of practising self-management skills. Improvement in walking ability was one of the most frequently identified changes, with many patients reporting a considerable difference given the fact that they had been used to sitting or lying to avoid the occurrence of pain.

“I start off with walking, first few times, like 15 minutes. Now I can walk for 35 minutes with no pain. My sleep is alright as well. I can sleep like a baby now.” [Patient 13, 56 years old female]

Meanwhile, patients identified that being able to cope with pain and related problems was also a contribution made towards the wellbeing of other people, for instance, their partners or carers. Some patients reflected how their condition had generated a situation of dependence and a possible burden for others, which had sometimes weakened their self-esteem. Therefore their improved ability helped them develop a new sense of identity, and a sense of having the capability and capacity to offer help to others.

“I’ve always looked after myself, so for me, if I can do anything towards that, for me that’s the fundamental part of my life. I’ve always done that, you know, I’ve been a single parent for many, many years so I don’t want to have to continually be going backwards and forwards to... for help. I don’t want to be dependent on anybody, so... and I feel that this (pain clinic) gives me that.” [Patient 1, 52 years old female]

6.9.3.2 Having a better QoL

Most of the changes and improvements discussed above could be classified as benefits in the QoL. This was also mentioned in different ways by most of the patients, covering the improvements in their ability to cope with the pain, different experiences on physical and psychological functioning, and being able to lead a normal life.

“Now with these exercises, with this flexibility it makes it a lot easier to do many things that you normally do in your life, you know.” [Patient 9, 43 years old male]

For some patients, their positive changes and confidence also drove them to pursue new directions in other parts of life and look forward to the future, including education, work and relationships, by valuing positive aspects of themselves and enjoying life again.

“I am actually starting soon voluntary work with elderly aged and those with Alzheimer’s. There’s no moving and handling jobs involved. They give you a mobile phone, you phone the carer to see if the carer’s ok.” [Patient 10, 59 years old female]

“Oh yes, I can go out. I finally went to see my friend after 15 years. It was a very good experience. I spent nearly half a day with her. It happened twice now. And we plan to meet again.” [Patient 13, 56 years old female]

6.9.4 Theme summary

Patients’ experiences of positive changes after their attendance in this pain clinic were explored in this theme. The improvements in their psychological and physical status were frequently identified. Their mindset and emotional wellbeing were improved, enabling them to be calmer and more relaxed, and less stressed about their condition. Patients were also more able to cope with their condition and medications, and minimise the impact of other challenges in their lives, enabling them to experience a better QoL and explore new directions. Some patients also reflected on their experiences of how the change in their mindset could influence their self-management behaviour. Some patients also described that their increased ability to lead a normal life contributed to others’ wellbeing. Being able to manage the pain and undertake easy housework made patients feel a sense of independence. Rather than being a recipient, patients who gained benefits were more confident to be a giver.

It was also noted that the extent of change in these patients was different. Some identified a more gradual and cumulative process while others experienced rapid benefits. However it seemed that patients who experienced less pain also gained benefits in their emotional health, but not all patients who experienced changes in their mindset or emotional health necessarily had an improvement in their pain experience. It seemed that thinking differently and having a positive mindset about self-management of chronic back pain was highly likely to support and facilitate the application of self-management skills.

6.10 Triangulation

In the methodology chapter, the mixed methods approach was introduced and the rationale for the choice of explanatory sequential design was presented. A major advantage of using mixed methods was that triangulation enhanced the validity of the study. In this study, a quantitative phase that included collecting and analysing quantitative data was designed and implemented during the first step. In the second step, the author connected the point of interface for mixing by identifying specific quantitative results that called for additional explanation and used these results to guide the development of the qualitative phase. The use of triangulation was introduced in Chapter 4 as a means of increasing the trustworthiness of the qualitative phase. This section has been included to demonstrate triangulation that results from using two methods within the same study, to further interpret to what extent and in what ways the qualitative results explained and added insight into the quantitative results.

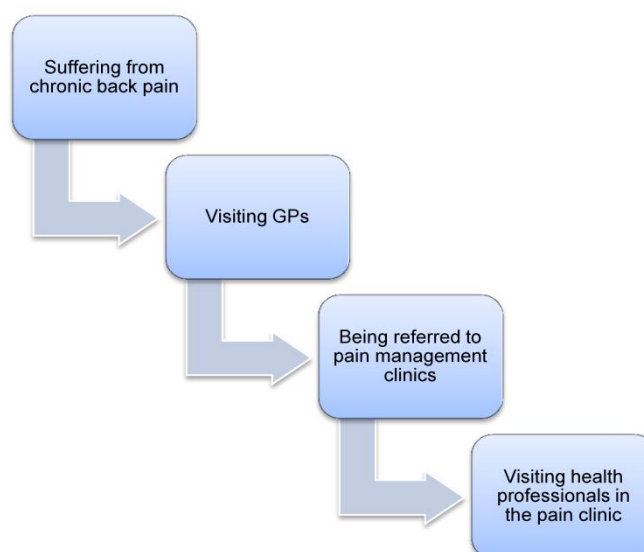
Triangulation of methods and data was achieved using two main strategies. Firstly, triangulation was undertaken by comparing each patient's interview transcript in the qualitative phase with their individual responses to the questionnaires in the quantitative phase. Secondly, the emergent codes, categories and themes in the qualitative phase were further compared with the associations detected in the

quantitative modelling. This confirmed that there was a consistency between their responses in both quantitative and qualitative phases, and the results were found to be reliable for building a coherent explanation for the quantitative results.

6.11 Connection of the themes and chapter summary

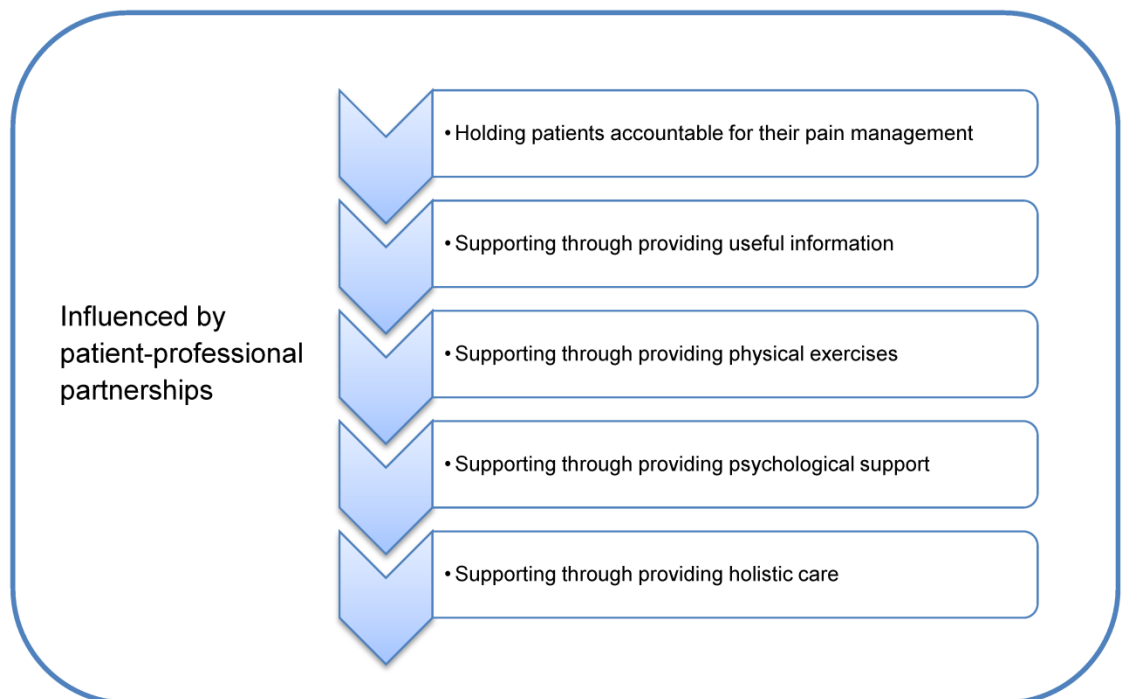
There are a total of six themes explored in this chapter based on the qualitative interviews conducted with 26 patients with chronic back pain. These themes are presented in a chronological sequence, starting from patients' experiences of living with pain before their attendance in the pain clinic, to receiving care and support provided by health professionals in the clinic, and experiencing a change after their attendance in this clinic. As was discussed in 6.3, this process of describing patients' experiences is not a "one-off" progression, but a description of connected experiences that may cycle round repeatedly at a certain stage. Based on the findings in the first three themes, Figure 6.1 presented below illustrates the health care pathway experienced by patients with chronic back pain, linking them to health professionals in pain management services.

Figure 6.1 Health care pathway linking patients to health professionals in pain management services



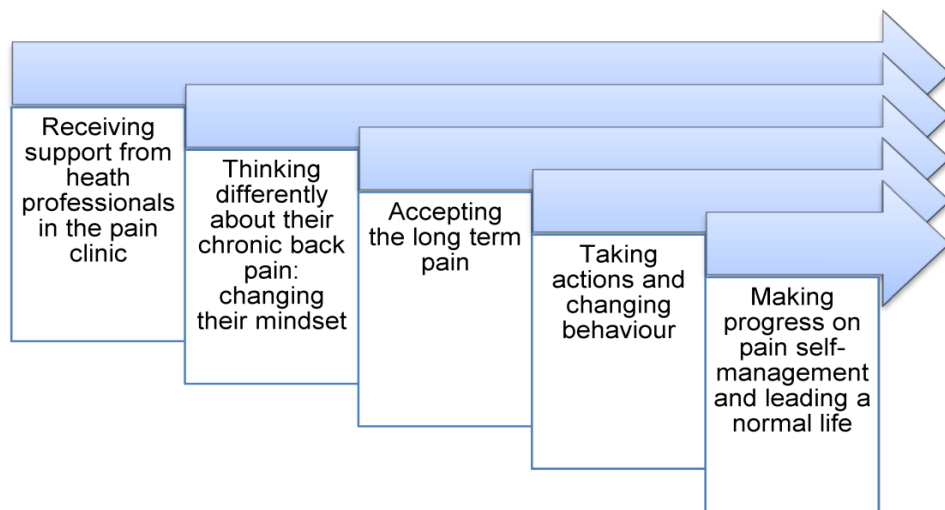
After patients had been referred to the pain clinic, the findings of this study informed the approaches to which health professionals provided self-management support for patients. As demonstrated in Figure 6.2, health professionals in the pain clinic supported patients in five approaches as identified by patients. The quality of their support however could be largely influenced by their partnerships with patients, and patients could receive good support from health professionals when there was also a good patient-professional partnership.

Figure 6.2 Health professionals' support on self-management in pain management services



With self-management support on chronic back pain provided by health professionals, patients reported positive changes experienced in their daily life. Most patients described that they felt changes in their mindset, enabling them to face the reality and accept the nature of their long term condition. This then further led them to take action for self-management and change their behaviour for a better QoL. Based on this, the following Figure 6.3 highlights the theoretical model of experiencing a change.

Figure 6.3 Theoretical model of experiencing a change



The above three figures present the themes relating to the health care pathway linking patients with chronic back pain to health professionals in the pain clinic, self-management support provided by health professionals, and theoretical model of how patients would experience a change after their treatment in the pain clinic. The core element that could largely connect these three processes was the patient-professional partnership, which started when patients accessed the pain clinic, then continued to influence the delivery of self-management support, and assist patients to pursue positive changes. Those factors, facilitators and barriers, identified by patients also influenced the degree of how effective health professionals' support could be received by patients. For instance, health professionals could help patients prioritise their goals and identify the personalised self-management skills when they fully understood patients' situations and health needs. Meanwhile, with support delivered based on a good partnership, patients were able to shift away from the idea of seeking a cure for their condition, to accepting the reality that they may have to live with the pain and attempting self-management for a better QoL. The positive perceptions could drive them further to experience a change in both psychological and physical health status, for instance, being able to feel relaxed and confident, and a reduction of the pain intensity.

Chapter 7 DISCUSSION

7.1 Introduction

The aim of this thesis was to explore patients' perceptions of the nature and influence of their partnerships with health professionals, on their ability to self-manage chronic back pain. A systematic review was conducted to identify any research that had been completed in this area. A mixed methods approach using explanatory sequential design was then used to address the overall aim. Based on this, a quantitative phase using a quasi-experimental design followed by a complementary qualitative phase using grounded theory was conducted, and the results of these two phases were presented in previous chapters.

This chapter presents the discussion and conclusion of this study. It begins with a specific discussion on study participants. Following this, an integrated discussion referring to the research objectives is also provided. A theoretical model that emerged from the findings of both quantitative and qualitative phases is presented, providing an overview of the findings and a basis for this integrated discussion. Based on this, the findings from these two phases are brought together to answer the overall research question and to explain how patient-professional partnerships may influence the self-management of chronic back pain. Facilitators of and barriers to a good patient-professional partnership are also discussed. The limitations of this study are then considered, followed by the key findings and conclusion of this thesis. Implications for further research, policy and practice are also provided. A brief personal reflection on the author's learning experiences throughout her PhD is presented at the end of this chapter.

7.2 Study sample: socio-demographic and clinical characteristics

In this current study, the mean age of the patients was 47.8 years (range: 19-84) with the majority being female (65.30%). A greater number of patients recruited were

unemployed (40.14%) compared with those who were in full-time employment (23.13%). These socio-demographic data are mostly consistent with participants in other studies investigating chronic back pain in the UK and other countries, such as the US (Von Korff et al., 1998; Moore et al., 2000), Canada (Mailis-Gagnon et al., 2007) and Australia (Blyth et al., 2005). The results of the Health Survey for England also showed a higher prevalence of chronic pain reported by females than males (Health and Social Care Information Centre, 2011). In studies conducted by Von Korff et al. (1998), Moore et al. (2000) and Mailis-Gagnon et al. (2007), the mean age of the participants attending self-management of chronic back pain groups was 49.4, 49.8 and 48.5 years, respectively; the majority of the patients were also being female (68.2%, 58.4% and 57.0%, respectively). Similarly, a study conducted in Australia showed that approximately 50% of the patients were aged 40 to 59 years old (no mean age available), and a greater proportion of females reported having chronic pain than males (Blyth et al., 2005). The negative impact on employment of those suffering with chronic pain was also widely recognised in other studies. In a survey in Europe of 4,839 adults with chronic pain (Breivik et al., 2006), it was reported that 61% of the population were less able or unable to work outside, 19% had lost their jobs and 13% had changed jobs due to their pain. The impact and burden of chronic pain in the workplace was also explored in a systematic review (Patel et al., 2012), which reported that chronic pain interfered with employment in 26% to 88% of patients.

All patients recruited in this study reported experiencing back pain for at least 12 months, with a mean duration of 8.3 years (SD=8.0). The most common pain locations in patients were the lumbar (73.5%) and sacral (87.0%) regions. These clinical characteristics are similar observations in other literature studying chronic pain in the UK and other countries in Europe and the Americas. A survey aiming to explore the prevalence, severity, treatment and impact of chronic pain in 16 European countries (Breivik et al., 2006) reported that the duration of pain was 5.9 years in the

UK. Pain sufferers in Finland had the longest duration of chronic pain (9.6 years), and Ireland had the shortest duration (4.9 years). In the Americas, the average pain duration of patients using self-management programmes was 6.5 years in Canada and 7.8 years in the US (LeFort et al., 1998; Mailis-Gagnon et al., 2007). The duration of pain may have been longer in this current study because the criteria for referral to the pain clinic were that patients had been living with pain for more than 12 months. Also, the length of time that GPs kept these patients under their care before making a referral to this clinic could not be standardised, given that a few patients had mentioned that they had had to repeat their referral requests to their GPs. In this study, the location of the pain site is also consistent with study figures reported in the European Survey. About half of the patients from 16 countries had pain in their back, and most of them specified that the pain was located in their lower back (Breivik et al., 2006). In another study conducted by Wetherell et al. (2011) in the US, the lower back (78.9%) and the lower extremity (79.8%) were reported as the most common pain areas. This may indicate that lower back pain is common in patients with chronic back pain. More resources and effort targeting lower back pain may be needed in the management of pain in primary care settings.

Most of the participants (87.0%) took medication for pain relief in this study. A similar figure was reported by other studies, suggesting that a large number of patients use medication for the management of chronic pain (Kerns and Rosenberg, 2000). The European Survey reported that two-thirds of patients took prescription medication and half used non-prescription analgesics. Only 2% of patients were under the care of pain management specialists (Breivik et al., 2006). This suggests that taking medication is still the predominant intervention used to control pain, and patients with chronic pain are generally unaware of self-management approaches, such as relaxation and distraction (Schofield, 2006). However, all analgesics may cause side effects, and these side effects are referred to as a major barrier to pain control by 74%

of GPs in the UK (Stannard and Johnson, 2003). Therefore, a shift in pain management from using passive methods, such as analgesics, to active approaches which involve self-management, may be needed.

This study also showed that more than three-quarters of participants (77.7%) had a concurrent emotional disorder, with 24.3% reporting anxiety, 6.8% reporting depression and about half (46.6%) reporting both. Patients in the interviews also described the significant impact of chronic back pain on their mental health, leading to anxiety and depression. In turn, they were also aware that their anxiety and depression could significantly contribute to their pain intensity. In line with these findings, there are a number of relevant studies that have observed an association between psychological factors and the occurrence of chronic back pain (Andersson, 1997; Wörz, 2003; Elizabeth Rippentrop et al., 2005; Gormsen et al., 2010). A World Mental Health Survey carried out in 17 countries suggested that mental disorders are associated with chronic back/neck pain, and the strength of this association is greater for mood and anxiety disorders than for alcohol abuse or dependence (Demyttenaere et al., 2007). In another study conducted by Polatin et al. (1993), which included 200 patients with chronic back pain, more than half of the patients (59%) showed at least one psychiatric diagnosis. These findings further highlight the fact that chronic pain is a biopsychosocial condition involving a complex interaction of biological, psychological and social factors in patients (Gatchel et al., 2007).

The comparison and discussions above indicate that the socio-demographic and clinical characteristics of the sample in this study represent a typical population with chronic back pain. Therefore, despite the limitations of this study (discussed later), the findings are likely to be generalisable to the chronic back pain population.

7.3 Integrated discussion

This PhD study began with a systematic review of the relevant literature, which enabled the author to identify the research gap. Whether and how patient-professional partnerships influence the self-management of chronic back pain still remained unknown. Two research objectives were thus proposed to address this gap:

1. To assess the influence of patient-professional partnerships on patients' ability to self-manage chronic back pain and to identify any associations between them.
2. To explore patients' perceptions and experiences of the influence of partnerships on their ability to self-manage the pain.

The results of the quantitative phase addressed the first research objective, indicating that patients' reports of having a good partnership with health professionals were significantly associated with their self-management ability. The results of the qualitative phase addressed the second research objective by identifying a series of facilitators of and barriers to a good patient-professional partnership, and five supportive approaches that health professionals used to help patients to self-manage their pain for a better QoL. As a mixed methods study, these results were then integrated into a theoretical model illustrating the nature and influence of partnerships with health professionals on patients' ability to self-manage chronic back pain.

7.3.1 Theoretical model

Figure 7.1 The integrated theoretical model for ‘how patient-professional partnerships influence the self-management of chronic back pain’

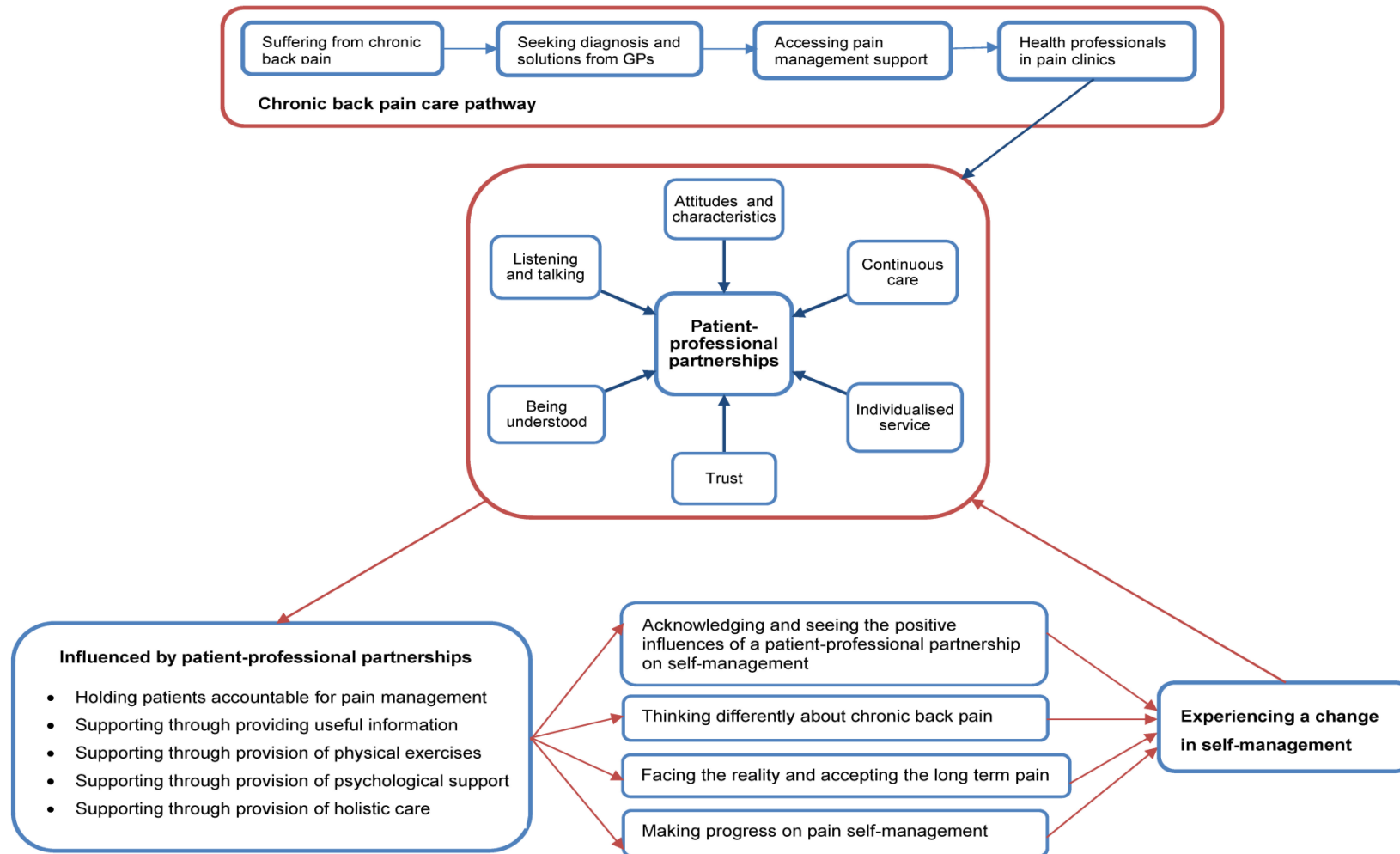


Figure 7.1 presents an integrated theoretical model, as a result of the triangulation of data and methods from the systematic review through to the mixed methods study. The top red box represents the pathway through which patients with chronic back pain sought help and were referred to pain management clinics in primary care. The red box in the middle represents the themes developed from the systematic synthesis, which also reflects the facilitators of a good patient-professional partnership identified by patients in the qualitative interviews. The bottom boxes and arrows illustrate the findings that were triangulated by methods and data in the mixed methods study. They also link the positive associations detected in the quantitative phase to themes and categories identified in the qualitative interviews. Findings from both phases systematically explain how health professionals' support and partnerships with patients may underpin the development of patients' self-management ability and enable patients to experience positive changes in physical and psychological health status. In this model, a good patient-professional partnership is presented as a fundamental driver, influencing health professionals' support provided through the five approaches: holding patients accountable for pain management; supporting through providing useful information; supporting through providing exercises; supporting through providing psychological support; and supporting through providing holistic care. When a good partnership is established, patients may benefit from health professionals' support directly; for example, patients physical functioning could be improved by practising exercises recommended. In turn, when patients experience improvements in their condition, their trust in the health professional is highly likely to grow, helping to further strengthen their partnerships. Frequently, a good partnership influences the self-management in an indirect approach. Patients' perceptions and beliefs are affected gradually by receiving relevant knowledge and information. This is then followed by a change in their mind set, from pursuing a permanent cure to 'facing the reality', accepting their long term back pain, and being willing to manage the pain.

This pivotal change in their beliefs contributes to the development of their capability and capacity, enabling them to make progress on self-management and realise that it is possible to live a normal lifestyle with their condition. The findings and themes presented in this model are a set of connected features of patients' experiences that may cycle round repeatedly at different stages. During the early stage of treatment in pain clinics, the interactions between partnerships and health professionals' support may need to be focused. As treatment continues, the changes in patients' perceptions and beliefs may be worth exploring by health professionals, enabling improvement in self-management. Hence it may be important to understand the priorities by assessing patient-professional partnerships and patients' self-management ability at different stages, in order to accelerate the process.

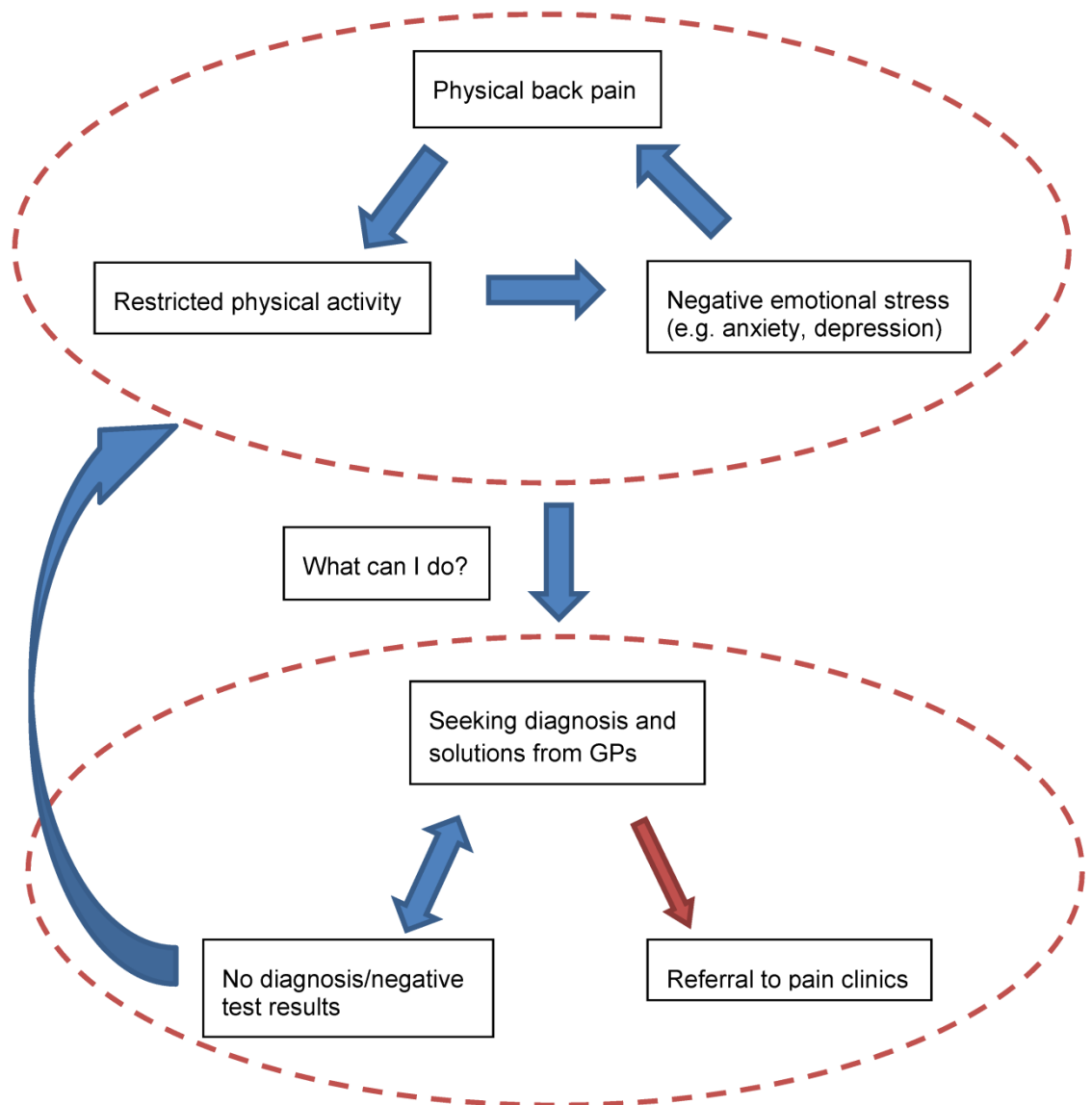
7.3.2 Understanding chronic back pain clinic access

The theory of 'how patient-professional partnerships influence the self-management of chronic back pain' highlights clinical pathways for patients to access pain management clinics. Although this study showed that patients' self-management ability increased after a three-month treatment in the pain clinics, there is still a large population with chronic back pain who are not under a pain management service, and difficulties still exist that may impede patients' access to pain clinics (Breivik et al., 2006). Based on patients' experiences identified in this study, the nature of chronic back pain and GP's inadequate knowledge of it are reported as two major reasons that often delay patients' referrals to pain management services. Similar barriers have also been highlighted in other studies exploring difficulties in accessing pain management clinics (Lansbury, 2000; Upshur et al., 2006).

Chronic back pain tends to be difficult to manage, not only because of its impact on physical functioning, but also because of its complex interaction with psychological factors that influence patients' reaction to pain (Melzack, 1999; Gatchel et al., 2007; Roditi and Robinson, 2011; Stoney, 2013). Consistent with this, anxiety/depression

was the most frequent comorbidity reported by patients (42.70%) involved in this study. However, according to their responses to the HADS scale, more than three-quarters of the patients (77.67%) suffered with anxiety/depression. This suggests that about 35% of patients did not realise the negative psychological impact of their chronic back pain. This lack of awareness may hinder their self-management progress. The interaction of a patient's mind and physical body and how they perform and respond together to experience the feeling of chronic back pain has been described by Siegel et al. (2002) as the chronic back pain cycle. This cycle may start with a physical injury or accident, which restricts a patient's physical activities and impedes their normal lifestyle. Patients are then likely to be emotional or upset about their inability to carry on their lives as before, leading to stress, anxiety and depression. The experience of the chronic back pain cycle and the process of accessing the pain management clinic are illustrated in Figure 7.2.

Figure 7.2 Chronic back pain cycle and pain clinic access



This figure shows the connection of a patient's mind and body response to their condition and the process of how chronic back pain is managed within primary care, based on patients' experiences. It also highlights the impact of pain management within primary care on patients' experience of seeking solutions. All of the patients involved in this study had had the experience of visiting their GPs for diagnoses and management. However, most of them reported that no clear or straight answers were provided by their GPs, but they were prescribed medication for pain relief. Such repeated visits and negotiation processes may create extra worry and negative emotional stress, leading to an increase in patients' anxiety and depression disorders.

This suggests that GPs may lack specialised knowledge of chronic back pain treatment. Given the fact that GPs only have a limited consultation time with each patient, there may also be a lack of communication and understanding between patients and GPs. This has also been echoed in some patients' experiences, resulting in a situation where patients kept visiting different GPs who, in turn, prescribed more medication to the patients. Although it was not the intention to explore how patients had been referred to the pain clinics, patients volunteered their experiences of actively negotiating the need for additional care and pushing for a referral from their GPs, and how this negotiation had possibly influenced their condition. Some patients thought that their GPs did not believe or understand their condition and life situations, while others felt that they sometimes lacked compassion or interest in providing further treatment. Consequently, with the progress of their condition and no improvement received, patients lost trust in their GPs and returned back to the pain cycle. A similar process has also been highlighted in a conceptual model established in a meta-ethnography study including 77 studies conducted by Toye et al. (2013). They related the lack of a diagnosis or failure to gain improvement from the health system to patients' sense of feeling their health professionals did not believe them. This then brought those patients back to the starting point, re-seeking the cause of their condition and potential solutions, which could mean that patients might have to repeat the struggle with their health professionals for diagnosis and investigations. In addition, some of the patients in this present study reported that incorrect information about the type of care provided by this pain clinic was given by their GPs when issuing the referral, causing confusion and disappointment. This shows the fact that GPs may also lack specific knowledge of and understanding about the services provided by this pain clinic. This may contribute to inappropriate referrals and create an extra financial burden on health services. Therefore, there is a need to improve GPs' knowledge of chronic back pain management by providing them with a structured and specialised training programme in chronic pain management, and a need to create referral

guidelines for patients with chronic back pain to reduce inappropriate referrals and the number of visits to GPs for analgesic prescriptions. Meanwhile, it may be useful and practical to set up community-based pain management clinics within GP practices, which can be managed by health professionals with specialised backgrounds and knowledge.

7.3.3 Factors influencing patient-professional partnerships

The theory of 'how patient-professional partnerships influence the self-management of chronic back pain' suggests that health professionals' support of self-management is influenced by patient-professional partnerships. This study revealed a number of facilitators of and barriers to a good patient-professional partnership (see Figure 7.3). Many of these factors strongly echo those identified in the systematic review carried out for this study (Fu et al., 2015).

Figure 7.3 Factors influencing patient-professional partnerships



* Facilitator/barrier identified by patients

Figure 7.3 presents both facilitators of and barriers to a good patient-professional partnership. The factors shown in the rectangular box on the left facilitate the development of a good patient-professional partnership, and those on the right lead to the development of a poor patient-professional partnership. Among these factors, an individualised approach was highlighted by patients, who perceived that the use of such an approach was a facilitator, and the lack of it was a barrier to a good partnership. In line with this, the double-headed arrows represent the reciprocal nature between these facilitators and barriers, although the opposite side of these

other factors was not directly highlighted by patients. It may be important to understand that not only these facilitators identified by patients, but also the opposite of the identified barriers are necessary for establishing a good patient-professional partnership in pain management.

It is also worth noting that these influential factors, identified by patients may overlap. The desired attitudes and characteristics of health professionals, for example, being professional and knowledgeable and friendly and sympathetic, reflected patients' needs for both physical and psychological support from health professionals. The appropriate attitudes of patients, including being optimistic and able to accept the nature of their chronic condition, could help reduce the gaps between health professionals and patients' perceptions of pain and their expectations of the treatment. While health professionals often provide ongoing support to patients with chronic conditions, patients expect a permanent cure (Harrison et al., 2001). Therefore, holding desirable attitudes and characteristics could help create a comfortable environment in which to talk, enabling a good first encounter for both health professionals and patients. The willingness to listen to patients is also an important and desirable attitude, which may encourage patients to share their experiences of living with pain and encourage them to express their expectations of the service. This could also enable health professionals to have an in-depth understanding of patients' history of pain and their current health needs. The ability to talk to patients with detailed information on their specific difficulties can be seen as a sign of individualised care, enabling patients to build their trust in health professionals. Meanwhile, any benefit or improvement gained in patients' health outcomes also contributes to patients' trust, driving their desire to pursue continuous care with a particular health professional.

Patients' expectations could be explored in the initial consultation when setting goals, which would help health professionals to understand patients' expectations and needs.

Supporting patients with what they need largely reflects the application of an individualised approach, in which patients are central to the treatment and care. Health professionals' full understanding of patients' situations and lifestyles is also helpful for applying an individualised approach, enabling health professionals to identify the most appropriate management skills to address patients' specific difficulties. A lack of sufficient time could potentially hamper every procedure mentioned above, in particular, the quality of the communication between health professionals and patients. This could impede the development of health professionals' understanding of patients' situations and expectations, the use of individualised approaches, and access to continuous care.

7.3.4 The influence of partnerships on patients' ability to self-manage their pain

As shown in the theory 'how patient-professional partnerships influence the self-management of chronic back pain', this study suggests that a good patient-professional partnership positively influences patients' self-management ability through five approaches used by health professionals to deliver self-management support.

7.3.4.1 Associations between patient-professional partnerships and the self-management of chronic back pain

In order to develop a good partnership, it has been suggested that both patients and health professionals concentrate on interpersonal relationships and sharing responsibility for health outcomes (Enehaug, 2000; Lake and Staiger, 2010). This may require health professionals to play a role in facilitating patients in managing pain better, providing self-care education, recommending preventive strategies and minimising pain interference throughout adulthood (Leslie, 2000). Consistent with this, the results of this study revealed that patient-professional partnerships had a

significantly positive impact on overall self-management ability and knowledge, capability to recognise and manage signs and symptoms and adherence to pain-related treatments. This indicates that having a good patient-professional partnership is highly likely to promote patients' self-management education. Self-management education embedded in a patient-professional partnership differs from traditional patient education, which focuses solely on health professionals teaching and passing on disease-specific skills and information. Self-management education, on the other hand, allows patients to identify their problems and provides specific techniques and other alternative skills to support decision-making to solve problems that are relevant to the consequences of chronic conditions in general (Bodenheimer et al., 2002). In this pain clinic, health professionals provided self-management education through extensive discussions with their patients. For instance, patients reported that health professionals supported them with an individualised and holistic care approach. They also provided their patients with written material to improve their knowledge of pain management, such as *The Pain Toolkit* (The Pain Toolkit, 2013) and the *Pain Management Plan* (Npowered Ltd., 2010), and demonstrated simple exercises, such as Tai Chi and Pilates, for patients to practise at home. Therefore, a good partnership between health professionals and patients with chronic back pain may result in an increase in patients' knowledge of their conditions and coping skills. However, considering that no association was detected between partnerships and patients' ability to manage the side effects of pain on their physical activity, spiritual wellbeing, and social life, these results may suggest that health professionals in pain management services should also pay more attention to the management of the effects of patients' conditions, which may impede the development of a good patient-professional partnership.

Self-efficacy in this study was found to be significantly associated with patients' ability to manage the effects of pain, but with a limited impact on overall self-management.

Although previous literature often simply used the measure of self-efficacy as an effective predictor of one's self-management ability (Bandura, 1997; Nicholas, 2007; Barlow, 2013), there is no evidence to suggest which component of self-management is sensitive to the change in self-efficacy. To this extent, this study may explain the principle that increases in self-efficacy may predict higher self-management ability through enhancing patients' management ability of the effects of pain on their physical activity, spiritual wellbeing and social life.

This study further suggested that emotional disorders were associated with negative influences on patients' self-management ability. Specifically, patients suffering with both severe anxiety and depression disorders tended to have poorer knowledge and ability to manage the side effects of pain. In order to improve patients' self-management ability, more psychological approaches may need to be implemented in pain management clinics. Previous research also suggested that including psychological support in the management of chronic pain would reduce pain-related disability and increase self-management. Meanwhile, the information and coping strategies learned through psychological approaches enabled patients to be active participants in the management of their chronic pain (Roditi and Robinson, 2011).

The number of pain sites was not associated with the ability to self-manage; however, a positive significant association was demonstrated in patients' knowledge about their conditions. This finding may suggest that patients tended to access more information relating to pain when they were suffering with multiple pain sites. Therefore, patients with multiple pain sites may be the patients who are most likely to receive the most benefit from pain management services. This result may indicate that health professionals need to provide more care aimed at improving patients' ability in the other three dimensions, i.e., treatment adherence, recognising and managing symptoms and managing side effects, for patients suffering with multiple pain sites.

Considering that health professionals in the clinic had different backgrounds and expertise, it is interesting to note that visiting at least three different health professionals was positively associated with having the knowledge and ability to recognise and manage symptoms of pain, but there was no association with overall self-management ability, treatment adherence or managing side effects. This may suggest that visiting a wider range of health professionals may benefit patients through access to more information and knowledge on pain symptoms and how to recognise and manage their conditions. Meanwhile, more support from health professionals on motivating patients' adherence to treatment, and particularly on managing the effects of pain, may be needed in order to achieve the aim of improved self-management in patients with chronic back pain.

This study did not show any associations between pain severity or history of pain and self-management. This lack of association is consistent with the results in other studies on the self-management of chronic back pain, which suggested that average pain intensity was not related to self-management behaviour or self-efficacy (Kratz et al., 2011). There is no firm evidence showing the impact of chronicity of pain on patients' self-management ability. This may indicate that, it is still possible that a pain management programme can provide a reduction in the levels of pain of patients who have experienced a long history of back pain. This finding also corroborated a previous study, which suggested that reductions in suffering in a pain management programme are likely for patients with a long history of pain (Wells-Federman et al., 2002).

7.3.4.2 Patients' perceptions and experiences of the influence of partnerships on the ability to self-manage their pain

Five supportive approaches were identified in which health professionals delivered self-management support for chronic back pain in this study. It is worth noting that the use of these five supportive approaches is largely affected by patient-professional

partnerships. In particular, health professionals' successful support of pain management through these approaches is underpinned by factors that constitute a good patient-professional partnership. For example, patients suggested that a good patient-professional partnership involved health professionals' attitudes and characteristics (e.g., being knowledgeable); willingness to listen and talk with patients in order to understand patients' situations, needs and expectations; and the provision of continuous care. These components were also identified as having an influence on the success of health professionals' support. In this instance, having a good partnership acts as a platform, on which health professionals could deliver their support in a more effective way. However, difficulties in forming a patient-professional partnership still exist, mainly due to the gap between the policy ideals and the reality of routine practice (Cribb, 2011). Although research data continue to show some signs of improvement in patients' empowerment, patients themselves do not feel as involved in their health care as they expected (Richards and Coulter, 2007; Sizmur and Redding, 2010). This may indicate that there is a lack of a standard programme guiding health professionals in how patients should be involved and what activities they should be involved in, enabling the development of a partnership in care in primary care. Having insufficient consultation time and a large number of patients may also restrict the development of patient-professional partnerships. Limited time could shorten the process of information sharing; the establishment of understanding and trust, which has an impact on individualised care delivery and access to continuous care. Research evidence suggests that patients feel more satisfied with the consultation length when health professionals are willing to listen and understand their situations (Ogden et al., 2004). This may suggest that more resources are needed to make consultations longer. Alternatively, it could also be managed by increasing the provision of self-management support in the form of self-referral to community-based pain clinics.

The importance of patient-professional partnerships in the self-management of chronic pain highlighted in this study is consistent with previous studies (Bodenheimer et al., 2002; Bair et al., 2009; Matthias et al., 2010; Matthias et al., 2012). The Chronic Care Model, which has influenced internationally both practice and research, stresses the necessity of building a partnership with health professionals for patients with chronic illnesses (Wagner et al., 2005). In this model, patients with chronic illnesses are encouraged to become more knowledgeable about issues affecting their condition and more actively involved in decisions about their health care. A more systematic and planned approach should be developed to support patients, on the basis of partnerships between active patients and proactive health professionals (Wagner et al., 2005). In order to promote the concept of a partnership in care, many studies have also made suggestions about health professionals' attitudes and characteristics, communication skills, knowledge and understanding of provision (Martin et al., 2005; Cooper et al., 2008; Barton, 2009). However, little has been said about what patients' attitudes and characteristics should be in a partnership. This study is valuable as patients also addressed the roles of patients in a partnership. Patients highlighted the importance of the acceptance of their chronic back pain, and the need to hold positive beliefs in order to cooperate with health professionals. This may also encourage them to explore new directions in order to self-manage their condition. The concept of acceptance has also received attention and been explored in a number of previous studies (McCracken et al., 2004a; McCracken et al., 2005; Stuifbergen et al., 2008). Acceptance of a chronic condition which is grounded in the perceptions of people suffering with a chronic condition has been considered as an alternative approach that concentrates on the adaptation to and acceptance of change in their lives (McCracken et al., 2005; Stuifbergen et al., 2008). In McCracken et al.'s study of evaluating the acceptance-based approach to chronic pain, they found that significant improvements in emotional, social, and physical functioning and health care use were shown in patients who accepted living with their chronic pain, and who were willing to engage in

daily activity regardless of the pain (McCracken et al., 2005). Meanwhile, it has been shown that acceptance of chronic pain is associated with better mental wellbeing, with fewer health care visits for pain management and fewer classes of analgesic medications being prescribed (Viane et al., 2003; McCracken et al., 2004b). Patients' recognition of their role and contribution in a patient-professional partnership has also been echoed in a recent study produced by Pomey et al. (2015), who suggested that the mutual contribution of both professionals and patients would strongly influence their partnership, driving them to explore practical solutions for addressing health problems that fit the patient-specific condition and situation. Therefore, it may be necessary to inform patients of their role in the self-management of chronic back pain. Patients with these attitudes and characteristics may be more likely to benefit from pain management clinics.

Some patients in this study expressed the concept of "talking is cure", highlighting the importance of communication with health professionals who were able to understand their difficulties, and its impact on their psychological health. The interrelationship between communication and understanding was also identified in the qualitative synthesis of this study (Fu et al., 2015). The talking cure has also been widely explored by Stilgoe and Farook (2008), who stated that conversation has always been a vital part of care, particularly for patients suffering from mental health problems and other conditions without clear diagnosis. In order to understand patients' specific health needs, Stilgoe and Farook (2008) suggested that dialogue and understanding might be the only elements of an effective conversation that would enable patients to feel comfortable and satisfied when interacting with health professionals. Although a conversation between health professionals and patients requires time, listening abilities, understanding and open-mindedness, it may also be necessary for this conversation to happen across the range of health professionals, including their GPs, nurses and others. Effective communication and continuity of care are both

fundamental factors contributing to the development of trust (McQueen, 2001; Mainous et al., 2001; Thompson, 2007; Karnieli-Miller and Eisikovits, 2009). Patients in this study expressed the belief that it is necessary to have a certain level of trust when establishing a good partnership with health professionals. Trust has been considered to be an important factor that could lead to an increase in patients' feelings of psychological safety (McQueen, 2001). However, building a trusting partnership is a process that develops over time. It can be challenging in situations where patients and health professionals barely know each other and may have different levels of knowledge, and expectations of the treatment of the condition (Whitney et al., 2006). In addition, it may also be challenging ensuring patients' continuity of care in practice, as no medically acceptable benchmarks for waiting times for the treatment of chronic pain exist globally (Lynch et al., 2007). Therefore, it is worth noting that first encounters, which may have a lasting effect, are important in influencing the emerging partnership as a first step, and any improvement gained during the treatment process is also essential for building trust with health professionals.

Self-management strategies were also discussed by patients in this study, including knowledge and information, written materials, physical exercises and relaxation skills. All these resources show that health professionals in the pain clinics do not just focus on pain itself, but also on other difficulties that patients may experience in their lives. It has been identified and valued by patients in this study where health professionals provided them with holistic care, treating them as a whole. For instance, health professionals helped them with their sleep patterns, diets and the demands of their jobs. This finding is of importance because such strategies may not be widely used in other similar pain services. For example, Cooper et al. (2009) showed that none of the reported self-management strategies used by their participants were cognitive in nature, such as relaxation. May (2007) and Liddle et al. (2007) suggested that physical exercises were still the predominant self-management skill used by patients

with chronic back pain. However, compared with general exercises, individualised home exercises have been suggested in previous studies as being more effective, reducing the level of pain and disability (Descarreaux et al., 2002). In addition, patients in this study argued "*it's not just one prescription fits all*"; therefore, a combination of different management strategies should be accessible for patients. Meanwhile, adequate and individualised support and advice from health professionals may enhance this process and help to prepare self-management care plans for patients (Cooper et al., 2009).

Patients' QoL significantly improved in this study, with positive changes in their psychological and physical status being frequently identified. It was also noted that the extent of these changes was different. Some reported a more gradual and cumulative process, while others experienced rapid benefits. However, it is interesting to recognise that patients who experienced less pain also gained benefits in their emotional health, but not all patients who experienced changes in their emotional health necessarily had any improvement in their pain experience. This finding also corroborated the results of the quantitative study. After the three months of treatment in the pain clinic, the number of patients with neither anxiety nor depression had increased, with significant improvement detected in the number of patients changing their anxiety and thought patterns. However, no significant improvement was detected in patients' pain severity. This may suggest that it is necessary to influence patients' perception and mindset prior to improving their physical pain. The interconnection between thoughts, feelings, behaviour and the resultant consequences has also been recognised in the core of Cognitive Behavioural Therapy (CBT) (Meichenbaum et al., 2009). CBT is a biopsychosocial approach often conducted through psychoeducation as an outpatient treatment for patients with chronic conditions (Bleijenberg et al., 2003; Meichenbaum et al., 2009). Patients participating in CBT are empowered by health professionals to identify their own agency in their emotional and behavioural

experiences and to develop skills to manage how their perceptions, feelings and behaviour interact and influence one another (Meichenbaum et al., 2009). Therefore, a good patient-professional partnership also appears to play an important role in CBT, encouraging patients to cope with their condition in a personalised way that is suitable for their bodies and mind. The use of CBT may also reflect the Self-Efficacy theory proposed by Bandura (Bandura, 1997; Bandura, 1986; Bandura and McClelland, 1977), which focuses on increasing patients' confidence in the ability to execute the behaviour necessary to produce specific performance attainments. This has also been echoed in this study, in that patients felt more confident and competent to practise self-management of chronic back pain, when they were supported by health professionals in a partnership. CBT approaches have been evaluated in a number of clinical pain studies, and results have suggested that CBT is effective in reducing psychological impact and pain and in improving functional activities (Morley et al., 1999; Turk and Meichenbaum, 1999). Therefore, the wider use of CBT approaches may be worth promoting in primary care.

7.4 Limitations

The findings of this study contribute to growing literature highlighting patient-professional partnerships and the self-management of chronic back pain, but several limitations need to be considered in interpreting the findings of this study.

For the quantitative phase, the major limitation was the design of the quasi-experimental study, which lacked randomisation and control groups. While the RCT is recognised as the gold standard for providing the most convincing evidence for evaluating the effectiveness of most clinical studies (Perencevich and Lautenbach, 2011), it was, however, neither appropriate nor practical for use in this study. The reasons for not taking forward the idea of using the RCT have been discussed in detail in Chapter 3 (3.4.1), where the rationale for the use of a one-group pretest-posttest design was given. However, there were threats to the internal and external

validity. For this study threats to validity, including history, maturation, instrumentation and multiple treatment interference, were of concern. History and maturation threats were taken into consideration in the quantitative data analysis by using hierarchical linear modelling, which allows for the control of unknown confounders. Meanwhile, the time interval between baseline and follow-up (three months) was relatively short in comparison with the history of patients' back pain. Instrumentation threat refers to the change in the outcome measures between baseline and follow-up that may affect the outcome. As described in Chapter 4, all questionnaires used in the quantitative study have good demonstrated validity and reliability. In addition, the same set of questionnaires was used by the author to collect patients' responses during both baseline and follow-up data collection, helping to minimise the threat to the internal validity of this study. The findings of the qualitative interviews supported the results of the quantitative phase, enabling the author to address, to some extent, these threats to internal validity. Multiple treatment interference occurs when participants receive more than one treatment; therefore, there may be a carryover effect between treatments, affecting the outcome of one single treatment. For this study, patients received support and care provided in the pain clinics; however some patients also took medication for pain relief during the same period of time. This may have potentially affected the effectiveness of the health professional's self-management support. In order to address this, medication taken for pain relief, together with other information about patients, was controlled using the hierarchical regression model when conducting quantitative data analysis.

The second limitation of this study was the sample size. The total number of 103 patients who completed questionnaires at both baseline and follow-up was small, making a Type II error possible. However, the intended sample size of 147 was calculated after accounting for a 25% dropout rate, and the use of the 103 completed cases still reached a 99% power level. The third limitation was that the sample of

patients was limited to those able to understand English, thus the generalizability to other cultural groups may be questionable. Although the outcome measures (such as PIH and PPIc) had shown good validity and reliability in earlier research, limited numbers of studies have used these measures in pain management clinics. This made this study difficult to compare with the results of other studies. In this study, all measures were patient self-reported, and there was a lack of information on patients' previous pain ratings. Therefore, patients may have under or overexpressed their pain severity (Kelly, 2001). Finally, it may be worth noting that data collected in this study were based on patients' perceptions only, and it would be useful to complement these with the views of health professionals in a future study.

For the qualitative phase of this study, a major limitation was that patients with negative or indifferent experiences of patient-professional partnerships and self-management were underrepresented. Despite efforts to target the recruitment, this qualitative phase did not succeed in recruiting many patients with negative opinions. Only two patients who showed a lower self-management score after treatment were recruited, but they provided valuable insights into how patient-professional partnerships may not always be helpful in supporting self-management. Based on their negative experiences, they also made useful suggestions to the pain clinic, helping health professionals to meet the expectations of patients with this type of experience. The low response of patients with negative experiences was unsurprising, as patients with no improvement or negative experiences were unlikely to continue their treatment, and would not be motivated to take part in research. Recruitment of patients with negative experiences was further limited by the inclusion criteria set for this qualitative phase which only included patients who had completed both baseline and follow-up data collection from the previous quantitative phase. Therefore, this limitation needs to be kept in mind when considering the transferability of the findings, as it is likely that the experiences represented are of those who have found self-

management support particularly beneficial. A further limitation of this qualitative phase was that the findings are based on patients' retrospective view of their journey with chronic back pain, before and after referral to the pain clinic. It was an unavoidable feature of the study design, which aimed to recruit patients who had participated in the previous quantitative study in order to gain insights into the influences of patient-professional partnerships on the self-management of chronic back pain. However, this limitation was overcome to some degree with the mixed methods study design, in which the quantitative phase showed congruence with the findings of the complementary qualitative phase. In addition, the author having a medical background may have introduced researcher bias when interviewing patients. However, the author clearly described her position in the study before the interviews. Several methods, for example, providing a rich thick description and peer reviewing, together with an in-depth description of all aspects of data collection and analysis were also provided, to ensure the accuracy and transparency of the qualitative findings.

7.5 Key finding of the thesis

This thesis comprises three main sections: a systematic review, a quantitative phase, and a complementary qualitative phase. All three sections support the notion that a good patient-professional partnership has a positive impact on the self-management of chronic back pain. The key findings are summarised below.

1. Findings of the qualitative systematic review and synthesis
 - a. A partnership between patients and professionals supports patients' self-management ability.
 - b. Seven factors within patient-professional partnerships influence self-management, including communication, mutual understanding, roles of health professionals, information delivery, patients' involvement, individualised care and healthcare service.

- c. Effective communication is a fundamental factor underpinning their partnerships in care.
2. Findings of the study
- a. A partnership between patients and health professionals supports patients' self-management ability, and effective communication appears to a fundamental factor underpinning their partnerships in care.
 - b. Patient-professional partnerships are associated with patients' ability to manage chronic back pain, and a good partnership positively influences the self-management of chronic back pain.
 - c. Patients suggested that it was necessary to build a good partnership with health professionals, not only in the pain clinics but also elsewhere.
 - d. Patients' self-management ability, partnerships with health professionals, self-efficacy, QoL, pain interference, and anxiety status improved significantly following three months of treatment in the pain clinic.
 - e. Patient-professional partnerships are also positively associated with patients' knowledge, adherence to treatment and ability to recognise and manage signs and symptoms.
 - f. Six facilitators of and five barriers to a good patient-professional partnership were identified. The six facilitators include: holding desirable attitudes and characteristics, having people to listen and talk with, being understood by health professionals, being able to trust health professionals, being treated as a person rather than a generic patient and having continuous care. The five barriers include: lacking sufficient information provided by health professionals, lacking of an individualised approach for the treatment, being treated differently from what patients expected, gaining no improvement, and being given insufficient consultation time with health professionals.

- g. A good partnership positively influences self-management ability, which can be achieved through five supportive approaches, including holding patients accountable for pain management and providing useful information, physical exercises, psychological support, and holistic care.
- h. Patients reported both psychological and physical benefits; however, most of the patients experienced positive changes in their mindset prior to gaining a benefit in their physical health.

7.6 Conclusion

This study has addressed the overall research aim by investigating the influences of patient-professional partnerships on the self-management of chronic back pain. Patients involved in this study had experienced at least 12 months of pain; the majority of the patients had multiple pain sites, took medication regularly and had an extensive history of investigation and treatment, for example, MRI or X-ray scans and physiotherapy. The fact that self-management advice and support provided in this clinic, based on patient-professional partnerships, increased their self-management ability was extremely positive. The results of this study not only confirm the theory proposed by Bodenheimer et al. (2002) that the patient-professional partnership enhances patients' ability to self-manage their chronic illnesses, but they also explain how a partnership can improve patients' self-management ability through supportive approaches.

This study also identifies a range of factors that facilitate a good partnership, including attitudes, communication, understanding, trust, individualised care, continuity of care and sufficient consultation time. These factors are considered to affect the way in which health professionals deliver their support of pain self-management, including holding patients accountable, providing information, physical exercises, psychological support and holistic care.

The results of this study support existing health policy in the UK, which highlights the importance of involving patients with long term conditions in the management and decision-making of their own care and treatment (Department of Health, 2013b). The findings also show good congruence with the Chronic Care Model, which emphasises the need to prevent health care for patients with long term conditions from focusing only on the condition. Instead, it is more beneficial to move to a system that focuses on a whole picture of the patient, providing self-management support through a patient-professional partnership (Wagner, 1997). The combination of both partnerships and self-management explored in this study provides empirical evidence, which also confirms the purpose of the EPP that aimed to develop self-management initiatives for patients with long term conditions, based on a good patient-professional partnership (Department of Health, 2001).

7.7 Implications for research, policy and practice

This study suggests that a good partnership between patients and health professionals is important and also necessary in the development of patients' self-management ability. A theory was generated to explain the positive association between patient-professional partnerships and the self-management of chronic back pain. However, more research is needed to determine the relevance and applicability of the theory to other patients with chronic pain as well as to other health care settings. Due to the limitation of the study design, further research using an RCT design is needed to assess the effectiveness of pain management clinics of this kind. Information on the socio-demographic and clinical characteristics of this study may be of importance in identifying a suitable control group. Given the fact that the sample size of 103 patients was small, and time interval between baseline and follow-up was relatively short, future studies are needed to verify the positive association between patient-professional partnerships and the self-management of chronic back pain in a larger sample size. More research is also needed to evaluate interventions designed

to improve patient-professional partnerships and the use of self-management programmes in the longer term. This study aimed to explore only patients' perceptions of their partnerships with health professionals, views and experiences of health professionals need to be investigated in the future to gain a broader understanding of the influences of patient-professional partnerships on self-management.

The findings of this study also suggest that there is a need to shift from a paternalistic culture in healthcare, to a paradigm that is about promoting partnership working between the health professionals and the patient in the management of chronic back pain in primary care settings. A range of factors influencing the quality of patient-professional partnerships were also identified in this study. Based on this and existing literature on patient-professional partnerships, a guideline on building a good patient-professional partnership should be available in the NHS. Also, given the fact that some patients were inappropriately referred to the pain clinics by their GPs, more work is needed to ensure GPs' expertise and knowledge on chronic pain management, and to further decide whether there is a need for the Department of Health to provide GPs with structured and specialised training programmes in pain management. Specific guidelines for making referrals to pain management clinics should also be developed to ensure that appropriate and opportune referrals are made for patients with chronic pain. Considering the psychological impact of chronic pain, it may be useful and practical for service commissioners to set up pain management clinics in the way that incorporates mental health specialists and/or therapists' services. Meanwhile, it may be beneficial to improve and accelerate access to self-management support for patients, for example through self-referral to pain management clinics.

In practice, it is important for both patients and health professionals to be aware of the necessity of good partnerships in care. Health professionals should pay more attention to communicating with patients and understanding their specific difficulties

and life situations, based on which individualised care can be developed and delivered. Rather than placing physical exercise as central, health professionals should take into account the patient's expectations and preferences when considering recommended treatments. There is also a need for health professionals to regularly assess the psychological functioning of patients, in order to understand their priority in the process of developing self-management ability. Clinical leads should also regularly gain feedback from patients and health professionals in terms of their partnerships, which may be useful for monitoring patients' self-management ability.

7.8 A reflective account: learning experiences during PhD

This section has been included to demonstrate the author's learning experience during her PhD. It focuses on how three years' research shifted her from a Master's student with less research experience to an independent researcher with both quantitative and qualitative research skills. This section also identifies how the author's beliefs and experiences have been affected as her research project progressed, providing transparency and information about her position in relation to this study.

This PhD journey provided me with an excellent opportunity to learn new research skills and to develop them further to an advanced level. My Master's dissertation was a narrative review of the involvement of children and young people in health and social research. Although this process developed skills in searching healthcare literature in different databases, I had only limited research training in conducting systematic reviews and synthesising health care literature. During my PhD I undertook training courses on "Working with literature", "Qualitative synthesis" and "Meta-analysis and Forest plots", from which I gained valuable knowledge and skills for conducting systematic reviews. This learning process supported me in completing a quality and efficient systematic review of this thesis. In addition, I used to consider myself as a qualitative researcher before my PhD, as I did not have much research

experience of capturing and analysing research data using a quantitative approach. However I have learnt a lot about quantitative research and the relevant skills and software over the last three years; for instance, I have attended courses on “Calculating Data”, “Manipulating Data” and “Statistics with SPSS”. These skills gave me the confidence to conduct different statistical tests and to run regression modelling in the quantitative phase of this study. I further developed my research skills in qualitative study by attending the training course on “In-depth interviewing skills” and “Nvivo beyond Fundamentals”. I no longer see myself as simply being competent in just one approach but as being more independent to undertake both qualitative and quantitative research.

This PhD experience has also provided me with a good understanding of the principles of research ethics and governance in the area of health research. Although I successfully obtained both ethics and R&D approvals, there were still some issues that I had not been aware of. The main challenge came with the ethics and governance application processes. I had to wait a considerable amount of time to obtain separate approvals from the National Research Ethics Service Committee and the Local Trust. Besides this, I was required to obtain DBS and Occupational Health checks in order to be issued a Research Passport, in which the University of Leeds shares pre-engagement information about me with the Leeds Community Healthcare Trust. Although I used this period of time well by writing up the systematic review chapter, on reflection, it may have taken less time if I started this at an earlier stage of my PhD journey.

This PhD study has developed my skills and ability to disseminate research to a range of audiences. I have published the systematic review in Health & Social Care in the Community, and have prepared manuscripts of the findings of both the quantitative phase and the qualitative phase for publication. I have also been actively contributing posters and presentations to conferences and seminars to communicate my study to

a number of internal and external researchers as well as to lay members (see Appendix xv). For example, I contributed posters to the Postgraduate Research Conferences and the 9th Congress of the European Pain Federation in 2015, and presentations to the Qualitative Discussion Group and Pain interests Group. I also presented a lay summary of my study to the Service User and Carer Involvement Advisory Group within the School of Healthcare.

My interpersonal skills have also been enhanced during this PhD study. One obvious improvement is that I have developed better face-to-face communication skills. I have also established extremely good relationships with health professionals and patients in the pain clinics. I often received positive feedback from many patients who appreciated the time I gave and the effort I made, and they thanked me for providing them with an opportunity to talk about their experiences. I believe this is an important skill for a successful researcher.

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APPENDICES

Appendix i Search strategy

1) CINAHL: 1980-2014

Search ID	Search Terms
S1	(patient* or inpatient* or outpatient* or client* or health professional* or health provider* or pain specialist* or doctor* or psychologist* or physiotherapist* or pain nurse* or occupational therapist* or pharmacist* or chiropractor* or osteopath*) AND (involv* or participat* or engag* or empower* or collaborat* or consult* or coproduc* or co-produc* or cocreat* or co-creat* or liais* or lias* or partner* or relation* or communicat*)
S2	(MH "Consumer Participation")
S3	(MH "Physician-Patient Relations") OR (MH "Professional-Patient Relations+") OR (MH "Nurse-Patient Relations")
S4	S1 OR S2 OR S3
S5	(self or individual* or personal) AND (manag* or care or caring or efficacy or support* or promot* or monitor* or decision* or control* or behavior*)
S6	(MH "Self Care+")
S7	S5 OR S6
S8	(chronic or long term) AND (back pain or spinal pain)
S9	(MH "Back Pain+") OR (MH "Low Back Pain")
S10	S8 OR S9
S11	S4 AND S7 AND S10

2) Cochrane: 1980-2014

Search ID	Search Terms
#1	(consumer* or customer* or user* or patient* or inpatient* or outpatient* or client* or health professional* or health provider* or pain specialist* or doctor* or psychologist* or physiotherapist* or pain nurse* or occupational therapist* or pharmacist* or chiropractor* or osteopath*) near/3 (involv* or participat* or engag* or empower* or collaborat* or consult* or coproduc* or co-produc* or cocreat* or co-creat* or liais* or lias* or partner* or relation* or communicat*):ti,ab,kw (Word variations have been searched)
#2	MeSH descriptor: [Consumer Participation] explode all trees
#3	MeSH descriptor: [Patient Participation] explode all trees
#4	MeSH descriptor: [Professional-Patient Relations] explode all trees
#5	MeSH descriptor: [Physician-Patient Relations] explode all trees
#6	MeSH descriptor: [Nurse-Patient Relations] explode all trees
#7	#1 or #2 or #3 or #4 or #5 or #6
#8	(self or individual* or personal) near/1 (manag* or care or caring or efficacy or support* or promot* or monitor* or decision* or control* or behavior*):ti,ab,kw (Word variations have been searched)
#9	MeSH descriptor: [Self Care] explode all trees
#10	MeSH descriptor: [Self Efficacy] explode all trees
#11	#8 or #9 or #10
#12	(chronic or long term) near/1 (back pain or spinal pain):ti,ab,kw (Word variations have been searched)
#13	MeSH descriptor: [Bck Pain] explode all trees
#14	MeSH descriptor: [Low Back Pain] explode all trees
#15	MeSH descriptor: [Pain Management] explode all trees
#16	#12 or #13 or #14 or #15
#17	#7 and #11 and #16

3) Embase: 1980-2014

Search ID	Search Terms
1	((patient* or inpatient* or outpatient* or client* or health professional* or health provider* or pain specialist* or doctor* or psychologist* or physiotherapist* or pain nurse* or occupational therapist* or pharmacist* or chiropractor* or osteopath*) adj3 (involv* or participat* or engag* or empower* or collaborat* or consult* or coproduc* or co-produc* or cocreat* or co-creat* or liais* or lias* or partner* or relation* or communicat*)).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
2	exp doctor patient relation/
3	exp patient participation//
4	exp nurse patient relationship/
5	1 or 2 or 3 or 4
6	((self or individual* or personal) adj1 (manag* or care or caring or efficacy or support* or promot* or monitor* or decision* or control* or behavio?r*)).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
7	exp self care/
8	6 or 7
9	((chronic or long term) adj2 (back pain or spinal pain)).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]
10	exp backache/ or exp low back pain/
11	exp spinal pain/
12	9 or 10 or 11
13	8 and 12
14	5 and 13
15	limit 14 to (english language and yr="1980 -Current")

4) Medline: 1980-2014

Search ID	Search Terms
1	((patient* or inpatient* or outpatient* or client* or health professional* or health provider* or pain specialist* or doctor* or psychologist* or physiotherapist* or pain nurse* or occupational therapist* or pharmacist* or chiropractor* or osteopath*) adj2 (involv* or participat* or engag* or empower* or collaborat* or consult* or coproduc* or co-produc* or cocreat* or co-creat* or liais* or lias* or partner* or relation* or communicat*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
2	exp Patient Participation/
3	exp Consumer Participation/
4	exp Professional-Patient Relations/
5	exp Nurse-Patient Relations/
6	1 or 2 or 3 or 4 or 5
7	((self or individual* or personal) adj1 (manag* or care or caring or efficacy or support* or promot* or monitor* or decision* or control* or behavio?r*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
8	exp Self Care/
9	exp Self Efficacy/
10	7 or 8 or 9
11	((chronic or long term) adj2 (back pain or spinal pain)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
12	exp Back Pain/
13	exp Low Back Pain/
14	11 or 12 or 13
15	10 and 14
16	6 and 15
17	limit 16 to (english language and yr="1980 -Current")

5) PsycINFO: 1980-2014

Search ID	Search Terms
1	((patient* or inpatient* or outpatient* or client* or health professional* or health provider* or pain specialist* or doctor* or psychologist* or physiotherapist* or pain nurse* or occupational therapist* or pharmacist* or chiropractor* or osteopath*) adj3 (involv* or participat* or engag* or empower* or collaborat* or consult* or coproduc* or co-produc* or cocreat* or co-creat* or liais* or lias* or partner* or relation* or communicat*)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
2	exp Client Participation/
3	exp Participation/
4	exp Involvement/
5	1 or 2 or 3 or 4
6	((self or individual* or personal) adj1 (manag* or care or caring or efficacy or support* or promot* or monitor* or decision* or control* or behavio?r*)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
7	exp Self Management/
8	exp Self Care Skills/
9	exp Self Efficacy/
10	6 or 7 or 8 or 9
11	((chronic or long term or non-cancer or non-malignant) adj2 (back pain or spinal pain)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
12	exp Back Pain/ or exp Pain Management/
13	exp Chronic Pain/
14	11 or 12 or 13
15	10 and 14
16	5 and 15
17	limit 16 to (english language and yr="1980 -Current")

Appendix ii A detailed critical appraisal of qualitative based research

Criteria	Jeffrey & Foster (2012)	Matthias et al. (2010)	Matthias et al. (2012)	Cooper et al. (2008)	Cooper et al. (2009)
Was there a clear statement of the aims of the research?	Yes – aims to understand how the personal experiences and feelings of physical therapists might influence their decision making when treating patients with low back pain.	Yes – to examine patient-NCM relationship by focusing on patient perceptions of their relationships with the NCMs and their physicians, in an effort to identify how these relationships may influence patients' self-management of their pain.	Yes - to ascertain perceptions of a multicomponent intervention tested in a randomized controlled trial for veterans with chronic musculoskeletal pain.	Yes – aims to define patient-centredness, in the context of physiotherapy for chronic low back pain, from the patient's perspective.	Yes – aims to explore chronic low back pain patients' perceptions of self-management following physiotherapy.
Is a qualitative methodology appropriate?	Yes – it is suited to understanding therapists' experiences.	Yes – this research focuses on exploring patients' perceptions on patient-NCM relationships, in order to find out how these relationships may affect their self-management of chronic pain.	Yes – it is to investigate participants' perceptions of an intervention for veterans with chronic musculoskeletal pain.	Yes – it is to explore the participants' perspective on physiotherapy, in order to define patient-centredness.	Yes - it is to explore chronic low back pain patients' perceptions of self-management and their experiences of physiotherapy.

<p>Was the research design appropriate to address the aims of the research?</p>	<p>Yes</p> <ul style="list-style-type: none"> • Justification given on the choice methodology. Rational was provided on the use of hermeneutic circle. • A purposive sampling was used to achieve breadth in the interview sample. 	<p>Yes</p> <ul style="list-style-type: none"> • Justification on employing focus group methodology was made. • Individuals who were randomised to the intervention aim and had participated in the pain self-management programme were invited. Other interested patients were purposively sampled based on sex, age, ethnicity and their perceptions. 	<p>Cannot tell</p> <ul style="list-style-type: none"> • No justification or discussion on conducting face-to-face interviews. • No information provided on employing grounded theory to guide data analysis. • Purposive sampling based on participants' treatment response to the intervention. 	<p>Cannot tell</p> <ul style="list-style-type: none"> • No justification or discussion on conducting semi-structured interviews. • No information provided on selecting the framework method of qualitative data analysis. • Purposive sampling frame: location of physiotherapy, sex, age, management style and physiotherapy course. 	<p>Cannot tell</p> <ul style="list-style-type: none"> • No justification or discussion made on conducting semi-structured interviews. • No information provided on selecting the framework method of qualitative data analysis. • Purposive sampling frame: location of physiotherapy, sex, age, management style and physiotherapy course.
<p>Was the recruitment strategy appropriate to the aims of the research?</p>	<p>Yes</p> <ul style="list-style-type: none"> • Purposive sampling • Participants' demographic details included • No justification of sample size provided 	<p>Yes</p> <ul style="list-style-type: none"> • Purposive sampling • Individuals who were randomised to the intervention arm and had participated in the pain self- 	<p>Yes</p> <ul style="list-style-type: none"> • Purposive sampling • Participants who were treatment responders and non-responders and non-completers were involved in 	<p>Yes</p> <ul style="list-style-type: none"> • Purposive sampling • Sampling criteria is clearly shown. • Participants' demographic details included 	<p>Yes</p> <ul style="list-style-type: none"> • Purposive sampling • It refers the reader to Cooper et al. (2008) for the details of participants recruitment

		<p>management programme were invited.</p> <ul style="list-style-type: none"> • No participants' demographic details included • No justification of sample size provided 	<p>this study. However, no explanations given why the non-completer were included.</p> <ul style="list-style-type: none"> • No participants' demographic details included • No justification of sample size provided 	<ul style="list-style-type: none"> • No justification of sample size provided 	<ul style="list-style-type: none"> • Participants' demographic details included • No justification of sample size provided
Data collection					
Setting for data collection	None	Several sites within one academic medical centre	None	Interviewee's home or in NHS premises	Interviewee's home or in NHS premises
Method for data generation	Semi-structured interviews	Four focus groups	Face-to-face interviews	Semi-structured interviews	Semi-structured interviews
Method for data generation explicit including development and piloting	Topic guide was attached. No information on its development or piloting.	Topic guide is provided, no information on piloting	Topic guide is provided, no information on piloting	Topic guide is available on request from the corresponding author. No information on piloting	Topic guide is provided, no information on piloting

Justification of methods chosen	Yes	Yes	None	None	None
Any modification of methods during the study and why	No	No	No	No	No
Clear format of the data collected	Clear – audio recorded	Clear – audio and video recording, with written notes	Clear – audio recording	Clear – voice recording and written notes	Clear – audio recording
Discussion around data saturation	Yes	None	Yes	None	None
Has the relationship between researcher and participants been adequately considered?	Yes	No	No	Yes	Yes • Although there is no information straight towards this, it refers the reader to Cooper et al. (2008) for full details of the methods and steps taken to overcome the

					limitations of this study.
Have ethical issues been taken into consideration?	Ethical approval sought; all participants and quotes are anonymised.	All participants and quotes provided are anonymised, but no information on Ethical approval.	All participants and quotes provided are anonymised, but no information on Ethical approval.	Ethical approval sought; all participants and quotes provided are anonymised.	Ethical approval sought; all participants and quotes provided are anonymised.
Data analysis					
In-depth description of the analysis process	Yes	No	Yes	No	No
Clear description of analysis process used or framework applied	Yes, hermeneutic circle was used. Three phases of interpretation and analysis were described.	Yes, using thematic content analytic techniques	Yes, using constant comparative methods guided by grounded theory	Yes, using framework analysis	Yes, using framework analysis
Clear description of derivation of	Yes	Yes	Yes	Yes	Yes

themes and categories					
Sufficient data to support findings	Yes	Yes	Yes	Yes	Yes
Consideration of any contradictory data that may have arisen	No	No	No	No	No
Researcher bias and potential influence considered	Yes	No	No	Yes	Yes
Is there a clear statement of findings?	Yes, results are clear and explicit. Evidence of three produced themes is provided and sufficient. The findings were also compared with previous literature.	Yes, results are clear and explicit. Evidence both for and against the researcher's arguments are provided and sufficient. Some participants have validated the findings.	Yes, results are clear and explicit. Evidence both for and against the researcher's arguments are provided and sufficient. No discussion on the credibility of these findings.	Yes, results are clear and explicit. Evidence both for and against the researcher's arguments are provided and sufficient. Findings are consistent with previous studies.	Yes, results are clear and explicit. Evidence both for and against the researcher's arguments are provided and sufficient. Findings are compared with previous studies.

<p>How valuable is the research?</p>	<p>The main findings were described. Maintaining patient-professional relationship was a key for physical therapists, and improving their communication skills may enhance their relationship with patients. Findings were compared with previous literature, and recommendations for future studies were made.</p>	<p>The contribution of this study is made. The implications of this study are illustrated, and the direct for future research is suggested. It adds to the robust literature on physician-patient relationship. Limitations are described.</p>	<p>The researchers discussed the contribution of this study, and also identified the new area that this study explored comparing with previous studies. Suggestions on future studies have been made. Limitations are described.</p>	<p>Research results are consistent with previous studies, and can be applied in similar settings. The implications are made, and the need of future research is suggested. Limitations of this study are discussed.</p>	<p>Findings are compared with previous studies. Suggestions on future studies have been made. Limitations of this study are considered.</p>
<p>Quality rating</p>	<p>Medium</p>	<p>Medium</p>	<p>Medium</p>	<p>Medium</p>	<p>Medium</p>

Criteria	Östlund et al. (2001)	Slade et al. (2009)	May (2001)	MacKichan et al. (2013)	May (2007)
Was there a clear statement of the aims of the research?	Yes – to explore the lay person’s perspective on the rehabilitation process.	Yes – to determine participants’ experience of exercise programmes for non-specific chronic low back pain.	Yes – to produce the range of dimensions of care that patients perceive are important in physiotherapy.	Yes - to describe patients’ experience of self-care for long term back pain and their views on provision of support for self-care.	Yes – to explore patients’ perspective and attitudes about back pain and its management.
Is a qualitative methodology appropriate?	Yes – it is to explore the participants’ perspective on the rehabilitation process.	Yes – it is to explore participants’ past experience of participating in an exercise programme.	Yes – it is to describe and understand patients’ experience of and attitude to healthcare.	Yes – it is to explore patients’ experience and their views.	Yes – it is to look at patients’ perspective and attitudes about back pain.

<p>Was the research design appropriate to address the aims of the research?</p>	<p>Cannot tell</p> <ul style="list-style-type: none"> • No justification or discussion made on conducting semi-structured interviews. • Grounded theory was used in order to capture people's experiences. • Theoretical sampling was used to select individuals based on sex, duration of sickness absence and the interviews content. 	<p>Yes</p> <ul style="list-style-type: none"> • Focus group design was selected because group interactions can trigger responses and build insights that may not arise during interviews. • The principles of Ground theory were used in the analysis. Coded themes and relationships between themes were identified. • Eligibility criteria were applied to identify the target population. 	<p>Yes</p> <ul style="list-style-type: none"> • Justification was made on the use of semi-structured interviews • Framework analysis was used, and the thematic framework was also developed to ensure that the identified themes were comprehensive and inclusive. • A purposive sampling was used to recruit people who had received physiotherapy for low back pain in the previous year. 	<p>Cannot tell</p> <ul style="list-style-type: none"> • No justification or discussion for conducting in-depth qualitative interviews. • No information provided on selecting the constant comparative method analysis. • Potential interviewees were selected based on age, sex and use of self-care. 	<p>Cannot tell</p> <ul style="list-style-type: none"> • No justification made for conducting semi-structured interviews. • Framework analysis was used for data analysis, and the five stages involved were clearly stated. Constant comparative analysis was used. • Sampling was undertaken systematically by choosing every fifth name from the patients discharge list to select participants.
<p>Was the recruitment strategy appropriate to the aims of the</p>	<p>Cannot tell</p> <ul style="list-style-type: none"> • Theoretical sampling • No participants' demographic details included 	<p>Yes</p> <ul style="list-style-type: none"> • Purposive sampling • Progress of selection for focus group study provided 	<p>Yes</p> <ul style="list-style-type: none"> • Purposive sampling • Participants' demographic details included 	<p>Yes</p> <ul style="list-style-type: none"> • Purposive sampling • Participants' demographic details included 	<p>Yes</p> <ul style="list-style-type: none"> • Purposive sampling • Participants' demographic details included

research?	• No justification of sample size provided	• No justification of sample size provided	• No justification of sample size provided	• No justification of sample size provided	• No justification of sample size provided
Data collection					
Setting for data collection	None	None	None	Interviewee's home or at the University	None
Method for data generation	Semi-structured interviews	Three focus groups	Individual interviews	Interviews	Individual interviews
Method for data generation explicit including development and piloting	No topic guide provided. The themes covered during the interviews were shown. No information available on piloting.	Focus group pre-determined questions were provided. But no information available on piloting.	Topic guide is reported on author's another article. No information available on piloting.	Topic guide is provided, no information available on piloting	Topic guide which was developed from a literature review and the study aims was provided. No information available on piloting.
Justification of methods chosen	None	None	None	None	Yes
Any modification of methods during the study and why	No	No	No	No	No

Clear format of the data collected	Clear - audio-taped	Clear - audio-taped and minuted	Clear - audio-taped, but these data were collected 8 years ago	Clear – audio recording	Clear - audio-taped
Discussion around data saturation	Yes	Yes	Yes	None	Yes
Has the relationship between researcher and participants been adequately considered?	No	No	Yes The participants were interviewed by a therapist about physiotherapy; however this did not stop those participants from providing negative comments.	Yes	No
Have ethical issues been taken into consideration?	Ethical approval sought; all participants and quotes provided are anonymised.	Ethical approval sought; all participants and quotes are anonymised.	Ethical approval sought; all participants and quotes are anonymised.	Ethical approval sought; all participants and quotes are anonymised.	All participants and quotes provided are anonymised, but no information on ethical approval.

Data analysis					
In-depth description of the analysis process	No	No	No	No	No
Clear description of analysis process used or framework applied	No, but the software programme and microanalyses are given.	Yes, using the principles of Grounded theory. The validity of the identified themes was discussed.	Yes, using Framework analysis, and its five stages are clearly provided.	Yes, using constant comparative methods.	Yes, Framework analysis was used, and the thematic framework was also developed to ensure that the themes identified were comprehensive and inclusive.
Clear description of derivation of themes and categories	Yes	Yes	Yes	Yes	Yes
Sufficient data to support findings	Yes	Yes	Yes	Yes	Yes

Consideration of any contradictory data that may have arisen	No	No	No	No	No
Researcher bias and potential influence considered	No	No	Yes	No	No
Is there a clear statement of findings?	Yes, results are clear and explicit. Evidence both for and against the researcher's arguments are provided and sufficient. No discussion on the credibility of these findings.	Yes, results are clear and explicit. Evidence of each identified theme is provided and sufficient. These themes were reviewed, compared and reached agreement by authors.	Yes, results are clear and explicit. Evidence of five themes is provided and sufficient. The findings were also compared with previous literature.	Yes, results are clear and explicit. Evidence both for and against the researcher's arguments are provided and sufficient. Findings are interpreted and compared with the literature.	Yes, results are clear and explicit. Evidence of four identified themes are provided and sufficient, only one theme is not considered further, as it is very limited in range of responses.
How valuable is the research?	The contribution of this study was discussed, but it indicated that the study goal may be too narrow.	This study revealed the importance of partnership in care and shared decision-making for people with non-	The researchers discussed the contribution of this study. A critique of this study had been discussed around its	The findings of this study are congruent with existing research. The implications of this study are described.	The contribution of this study was discussed. Another finding was that most patients expressed a

	Methodological considerations had been made. Suggestions for future studies had been made.	specific chronic low back pain, from patients' perspectives. Suggestions were made for future research and these exercise programmes.	credibility, transferability, dependability and conformability to ensure a rigorous and scientific qualitative approach. Findings were compared with previous literature, and directions for future studies were given.	Strengths and weaknesses of this study are illustrated.	desire to participate in the management of their problem and achieve self-management. Both findings were compared with previous literature. Limitations of this study were discussed, and directions for future studies were given.
Quality rating	Low	Medium	High	Medium	High

Back pain

At SpineFit ?

You are a very important person!

I would like to invite you to take part in this study and hear about your experiences at SpineFit .

This study will look at your relationships with the health care team and whether or not these influence your ability to manage your back pain.



What do I need to do?

Simple! You will only need to complete some very short questionnaires, which will take you less than 20 minutes. I would like to follow this by inviting you to take part in an informal interview about your experiences of relationships with the health care team. All information given by you will be anonymous and kept in confidence.



How can I take part?

You just need to contact the lead researcher Maggie Fu.



07809 759 652, 0113 343 3519



hcyf@leeds.ac.uk



3.35 Baines Wing, University of Leeds, LS2 9JT

DRIVING POSITIVE CHANGE

UNIVERSITY OF LEEDS

NHS
Leeds Community Healthcare
SpineFit

Appendix iv Patient information sheet



Leeds Community Healthcare **NHS**
NHS Trust

I would like to invite you to take part in a study, which aims to explore the influence of your partnerships with health care professionals on your ability to self-manage back pain. You are a very important person and your personal views on the relationship between you and your health care team are needed. In particular, I would like to hear more about how you think this relationship influences your ability to manage back pain. Please take some time to read the following information carefully, and if you wish, discuss it with your friends and family. Should you need any further information, please feel free to contact me (contact details can be found in the end).

1. What is the purpose of the study?

A new approach of working together in partnership has been developed between patients and health professionals. This study will look at your partnerships with the health care professionals and whether these influence your ability to manage back pain. It is hoped that the results will help us to improve how pain is managed by understanding and improving how these partnerships work.

2. Who is doing the study?

This study is funded and organised by the School of Healthcare, University of Leeds. The lead researcher is Ms Maggie Fu, a PhD student at the School of Healthcare, under the supervision of Prof. José Closs, Dr. Elaine McNichol and Ms Kathryn Marczewski.

3. Why have I been invited to take part?

You have been chosen because your General Practitioner (GP) has referred you to the pain clinic.

4. Do I have to take part?

It is totally up to you to decide. I will provide you with all the necessary information and answer all your questions related to this study. If you agree, I will then ask you to sign a consent form to show that you are willing to take part. You can withdraw from this study at any time without giving a reason. This will not affect the medical care you receive.

5. What will happen to me if I take part?

You will receive the usual care from the clinic. There are two parts to this study. Your participation in both parts is not compulsory, but you will need to participate in part 1 in order to continue to part 2.

Part 1:

This involves assessing how you self-manage back pain and your experience of partnerships with health professionals. You will be asked to complete four very short questionnaires. In total, this will

2 Chair: Neil Franklin

Chief Executive: Rob Webster



take you less than 20 minutes to complete. You will be invited to complete these questionnaires at the Health Centre twice: 1) straight after your first appointment at SpineFit; 2) three months later. If you have been discharged or referred to other places after your first visit to SpineFit within three months, I can send you the questionnaires by mail with a pre-paid self-addressed envelope.

Part 2:

A smaller number of people who have completed the questionnaires will be invited to be interviewed in more detail. This will involve an individual, informal interview with me about your relationships with health care team and how these have influenced your ability to manage pain. You may or may not be invited to be interviewed, but either way you will be contacted so that you know what is happening. Interviews will be conducted privately, either at the Health Centre or your home, whichever you prefer. I will send information about the broad areas that will be covered during the interview in advance, so that you can have some time to think about them. There are no right or wrong answers; I just want to hear about your personal experience. The interview is expected to last up to 60 minutes, and if you agree, it will be audio taped. You can choose to stop the interview at any time without giving any reason. I will still include the information you have already given me, unless you ask me not to. Your decision to participate in the interview will not affect the care you receive.

6. Will I be paid to participate in this study?

You will not be paid for taking part in this research.

7. What are the possible disadvantages and risks of taking part?

There are no risks specifically associated with participation in the study. A possible disadvantage is the time taken to complete the questionnaires and the optional interview.

8. What are the possible benefits of taking part?

The information you give will be used to help improve future partnerships between patients and health professionals. It may help you understand how to manage back pain. Feedback from participants who have been involved in previous research undertaken in SpineFit showed that they enjoyed their experience.

9. Will my taking part in the study be kept confidential?

Yes. All information about you will be handled in confidence. All information collected during the course of the study will be entirely anonymised. Only my supervisors (Prof. Closs and Dr. McNichol) and I will have access to your information. However, if you tell me something that gives me cause for



concern about your health or care, I will share this information with relevant healthcare professionals. In this case, your confidentiality may need to be broken when discussing your issues with them. There is a possibility of using direct quotes from the interviews but they will be anonymous. Your identity will not appear in any reports or publications.

10. What will happen to the results of the study?

This project is a key part of the researcher's PhD thesis. I will be happy to share the information about the findings when it is completed in 2016.

11. What if there is a problem?

If you have any concerns or complaints about the study, you can speak to me and I will do my best to answer your questions. Should you have a complaint about the way this study is being conducted, please contact the researcher's supervisor Prof. Closs (Tel: 0113 3436773, Email: S.J.Closs@leeds.ac.uk). You can withdraw from the study at any time without giving a reason.

12. Further information and contact details

If you require further information, please feel free to ask me any questions you wish.

Lead researcher: Maggie Fu; **Tel:** 0113 343 3519; **Mobile:** 07809 759 652

Email: hcyf@leeds.ac.uk

Address: Room 3.35, School of Healthcare
Baines Wing, University of Leeds
Leeds, LS2 9UT

Thank you for taking the time to read this information

Please keep this copy.

Appendix v Participant consent form



Leeds Community Healthcare 
NHS Trust


UNIVERSITY OF LEEDS

Patient Consent Form – Part 1

Patient-professional partnerships and back pain self-management

Lead researcher: Maggie (Yu) Fu

This is the initial consent form of this study, which will look at your relationships with the health care team in SpineFit and whether or not these influence your ability to manage your back pain.

Please tick box

1. I confirm that I have read and understood the information sheet.
2. I agree to complete the questionnaires (part 1).
3. I agree to be contacted about the interview (part 2).
4. I give permission to M. Fu to access my medical record.
5. 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.
6. I understand that data collected during this study may be looked at by the research team. I give permission for these people to have access to my records.
7. I give permission for my anonymised quotes and data to be used for research and teaching purposes on the understanding that my identity will be kept confidential.

Name of patient

Date

Signature

Researcher

Date

Signature

Chair: Neil Franklin

Chief Executive: Rob Webster



Patient Consent Form – Part 2
Patient-professional partnerships and back pain self-management
Lead researcher: Maggie (Yu) Fu

This form is to seek your consent for participation in the interview part of this study.

Please tick box

1. I confirm that I have read and understood the information sheet.
2. I agree to complete the interview (part 2).
3. I give permission to M. Fu to access my medical record.
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 data collected during this study may be looked at by the research team. I give permission for these people to have access to my records.
6. I give permission for my anonymised quotes and data to be used for research and teaching purposes on the understanding that my identity will be kept confidential.

Name of patient Date Signature

Researcher Date Signature

Chair: Neil Franklin

Chief Executive: Rob Webster

Appendix vi Study questionnaires

STUDY ID #: _____ DO NOT WRITE ABOVE THIS LINE HOSPITAL #: _____

Brief Pain Inventory (Short Form)

Date: ____/____/____ Time: _____


Name: _____
 Last First Middle Initial

1. Throughout our lives, most of us have had pain from time to time (such as minor headaches, sprains, and toothaches). Have you had pain other than these everyday kinds of pain today?


1. Yes 2. No

2. On the diagram, shade in the areas where you feel pain. Put an X on the area that hurts the most.

Right Front Left



Left Back Right



3. Please rate your pain by circling the one number that best describes your pain at its **worst** in the last 24 hours.

0 1 2 3 4 5 6 7 8 9 10
 No Pain Pain as bad as you can imagine

4. Please rate your pain by circling the one number that best describes your pain at its **least** in the last 24 hours.

0 1 2 3 4 5 6 7 8 9 10
 No Pain Pain as bad as you can imagine

5. Please rate your pain by circling the one number that best describes your pain on the **average**.

0 1 2 3 4 5 6 7 8 9 10
 No Pain Pain as bad as you can imagine

6. Please rate your pain by circling the one number that tells how much pain you have **right now**.

0 1 2 3 4 5 6 7 8 9 10
 No Pain Pain as bad as you can imagine

Page 1 of 2

STUDY ID #: _____ DO NOT WRITE ABOVE THIS LINE HOSPITAL #: _____

Date: ____ / ____ / ____ Time: _____
Name: _____
Last First Middle Initial

7. What treatments or medications are you receiving for your pain?

8. In the last 24 hours, how much relief have pain treatments or medications provided? Please circle the one percentage that most shows how much relief you have received.

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%
No Complete
Relief Relief

9. Circle the one number that describes how, during the past 24 hours, pain has interfered with your:

A. General Activity
0 1 2 3 4 5 6 7 8 9 10
Does not Completely
Interfere Interferes

B. Mood
0 1 2 3 4 5 6 7 8 9 10
Does not Completely
Interfere Interferes

C. Walking Ability
0 1 2 3 4 5 6 7 8 9 10
Does not Completely
Interfere Interferes

D. Normal Work (includes both work outside the home and housework)
0 1 2 3 4 5 6 7 8 9 10
Does not Completely
Interfere Interferes

E. Relations with other people
0 1 2 3 4 5 6 7 8 9 10
Does not Completely
Interfere Interferes

F. Sleep
0 1 2 3 4 5 6 7 8 9 10
Does not Completely
Interfere Interferes

G. Enjoyment of life
0 1 2 3 4 5 6 7 8 9 10
Does not Completely
Interfere Interferes

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Pain Research Group
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7 I keep track of my symptoms and early warning signs (e.g. blood sugar levels, peak flow, weight, shortness of breath, pain, sleep problems, mood):

0 1 2 3 4 5 6 7 8
Never Sometimes Always

8 I take action when my early warning signs and symptoms get worse:

0 1 2 3 4 5 6 7 8
Never Sometimes Always

9 I manage the effect of my health condition(s) on my physical activity (i.e. walking, household tasks):

0 1 2 3 4 5 6 7 8
Not very well Fairly well Very well

10 I manage the effect of my health condition(s) on how I feel (i.e. my emotions and spiritual wellbeing):

0 1 2 3 4 5 6 7 8
Not very well Fairly well Very well

11 I manage the effect of my health condition(s) on my social life (i.e. how I mix with other people):

0 1 2 3 4 5 6 7 8
Not very well Fairly well Very well

12 Overall, I manage to live a healthy life (e.g. no smoking, moderate alcohol, healthy food, regular physical activity, manage stress):

0 1 2 3 4 5 6 7 8
Not very well Fairly well Very well

Patient Partnership in care

0447a

113440-08847

NAME

You can help improve the quality of life for people living with long term conditions.
Your opinions are valuable.

Your feedback will help doctor/health professional
improve advice and support given to patients

- All information will be kept anonymous, so please give honest feedback

Please mark the box like this with a ball point pen. If you change your mind just cross out your old response and make your new choice.

Simply fill in the questionnaire, seal it in the envelope and return it to reception.

As a result of your visit to the doctor/health professional today, how would you rate the following:

Please tick which applies		Poor	Fair	Good	Very good	Excellent
1	The ability of your doctor/health professional to ask you what you wanted to talk about	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	The ability of your doctor/health professional to give you the information you wanted to know	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	The opportunity to talk about your concerns and fears	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	The ability of the doctor/health professional to really listen to you	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	Your understanding of your health condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	Your doctor/health professional's understanding of your personal situation when discussing your care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	Your understanding of how your health care will be managed as a result of today's visit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	Your doctor/health professional's support in helping you feel you can manage your care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9	The information given to you by your doctor/health professional about how to get answers to future questions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10	Your doctor/health professional's follow up on your health care from your last visit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11	Your partnership with your doctor/health professional in your care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Survey provided by



Please turn over ↶

Rev 1.0

After seeing your doctor/health professional today

Out of a scale 0 to 10 please rate the following

		<i>Example</i>													
	Not confident	0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	10	Very confident	
12	How confident are you that you can carry out what you and your doctor/health professional planned today?	Not confident	0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	10	Very confident
13	How important is it for you to maintain and improve your health?	Not important	0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	10	Very important
14	How confident are you that you can cope with your health condition in a day to day situation?	Not confident	0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	10	Very confident
15	How confident are you that the doctor/health professional will follow up on the plans you made today?	Not confident	0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	10	Very confident
16	How confident are you that you can do things to care for yourself?	Not confident	0	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	10	Very confident

Do you have any comments on things you and your doctor/health professional could do to help you to further manage your condition?

What extra support would be useful to you (for example information about support groups or organisations, or help with use of devices and equipment)?

The following questions give us general information about the range of people who have filled in this survey. This information will not be used to identify you and will remain confidential.

How old are you in years? Under 25 25 - 59 60+

Are you: Female Male

How often have you seen this doctor/health professional? First Visit More than once

Survey provided by



Rev 1.0

Hospital Anxiety and Depression Scale (HADS)



Name: _____ Date: _____

Clinicians are aware that emotions play an important part in most illnesses. If your clinician knows about these feelings he or she will be able to help you more.

This questionnaire is designed to help your clinician to know how you feel. Read each item below and **underline the reply** which comes closest to how you have been feeling in the past week. Ignore the numbers printed at the edge of the questionnaire.

Don't take too long over your replies, your immediate reaction to each item will probably be more accurate than a long, thought-out response.

A D			A D	
3		I feel tense or 'wound up'		
2		Most of the time	3	
1		A lot of the time	2	
0		From time to time, occasionally	1	
		Not at all	0	
	0	I still enjoy the things I used to enjoy		
	1	Definitely as much	0	
	2	Not quite so much	1	
	3	Only a little	2	
		Hardly at all	3	
3		I get a sort of frightened feeling as if something awful is about to happen		
2		Very definitely and quite badly	3	
1		Yes, but not too badly	2	
0		A little, but it doesn't worry me	1	
		Not at all	0	
	0	I can laugh and see the funny side of things		
	1	As much as I always could	3	
	2	Not quite so much now	2	
	3	Definitely not so much now	1	
		Not at all	0	
3		Worrying thoughts go through my mind		
2		A great deal of the time	0	
1		A lot of the time	1	
0		Not too often	2	
		Very little	3	
	3	I feel cheerful		
	2	Never	3	
	1	Not often	2	
	0	Sometimes	1	
		Most of the time	0	
0		I can sit at ease and feel relaxed		
1		Definitely	0	
2		Usually	1	
3		Not often	2	
		Not at all	3	
		I feel as if I am slowed down		
		Nearly all the time	3	
		Very often	2	
		Sometimes	1	
		Not at all	0	
	0	I get a sort of frightened feeling like 'butterflies' in the stomach		
	1	Not at all	0	
	2	Occasionally	1	
	3	Quite often	2	
		Very often	3	
	3	I have lost interest in my appearance		
	2	Definitely	3	
	1	I don't take as much care as I should	2	
	0	I may not take quite as much care	1	
		I take just as much care as ever	0	
	3	I feel restless as if I have to be on the move		
	2	Very much indeed	3	
	1	Quite a lot	2	
	0	Not very much	1	
		Not at all	0	
	0	I look forward with enjoyment to things		
	1	As much as I ever did	0	
	2	Rather less than I used to	1	
	3	Definitely less than I used to	2	
		Hardly at all	3	
	3	I get sudden feelings of panic		
	2	Very often indeed	3	
	1	Quite often	2	
	0	Not very often	1	
		Not at all	0	
	0	I can enjoy a good book or radio or television programme		
	1	Often	0	
	2	Sometimes	1	
	3	Not often	2	
		Very seldom	3	

Now check that you have answered all the questions

<p>This form is printed in green. Any other colour is an unauthorized photocopy.</p> <p>HADS copyright © R.P. Snaith and A.S. Zigmond, 1983, 1992, 1994.</p> <p>Record form items originally published in <i>Acta Psychiatrica Scandinavica</i> 67, 361-70, copyright © Munksgaard International Publishers Ltd, Copenhagen, 1983.</p> <p>First published in 1994 by nferNelson Publishing Company Ltd.</p> <p>Published by GL Assessment Limited, 389 Chiswick High Road, 9th Floor East, London W4 4AL.</p> <p>GL Assessment is part of the GL Education Group</p> <p>Code 0090002511</p> <p>Printed in Great Britain</p>	<p>TOTAL</p> <table border="1" style="width: 40px; height: 20px; margin-left: auto; margin-right: auto;"> <tr> <td style="width: 20px; text-align: center;">A</td> <td style="width: 20px; text-align: center;">D</td> </tr> <tr> <td style="text-align: center;"> </td> <td style="text-align: center;"> </td> </tr> </table> <p>13(7.13)</p>	A	D		
A	D				

5. I can do some form of work, despite the pain. ("work" includes housework, paid and unpaid work).

0 1 2 3 4 5 6
Not at all Completely
Confident confident

6. I can still do many of the things I enjoy doing, such as hobbies or leisure activity, despite pain.

0 1 2 3 4 5 6
Not at all Completely
Confident confident

7. I can cope with my pain without medication.

0 1 2 3 4 5 6
Not at all Completely
Confident confident

8. I can still accomplish most of my goals in life, despite the pain.

0 1 2 3 4 5 6
Not at all Completely
Confident confident

9. I can live a normal lifestyle, despite the pain.

0 1 2 3 4 5 6
Not at all Completely
Confident confident

10. I can gradually become more active, despite the pain.

0 1 2 3 4 5 6
Not at all Completely
Confident confident

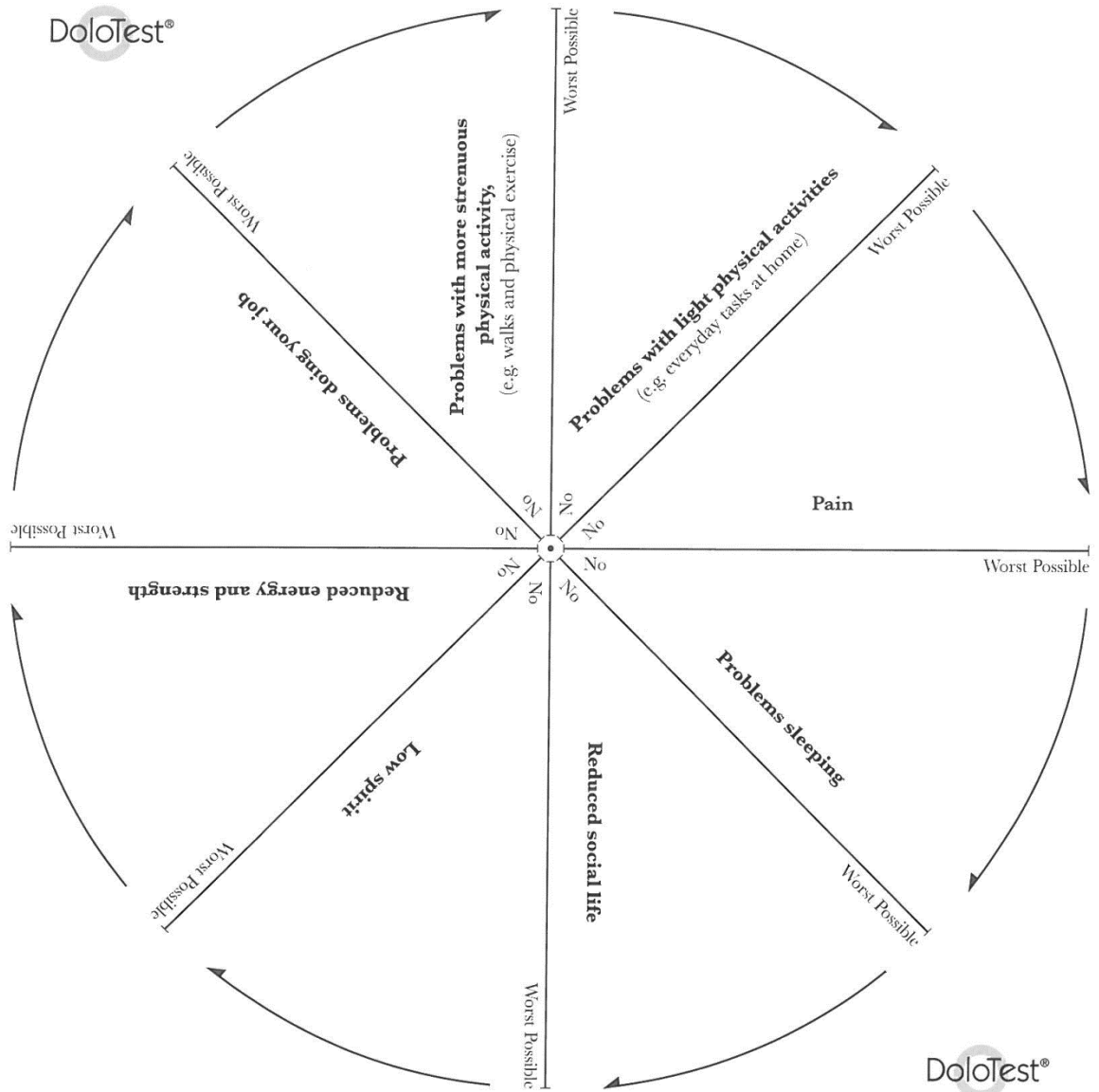
Source: Nicholas M.K. Self-efficacy and chronic pain. Paper presented at the annual conference of the British Psychological Society. St. Andrews, 1989.
Reprinted with permission from the author

Patient:

Social security number:

Date:

To what extent do you experience



Notes:

Appendix vii Reminder letter



Reminder

Patient-professional partnerships and back pain self-management

Dear Mr/Mrs _____

Thank you for taking part in my study. I very much appreciate your time and effort in completing the questionnaires about your pain.

This letter is to invite you to complete the same questionnaires once more next month on your visit to SpineFit. I will be there with you. Your continued participation is very important as it will enable us to compare your answers with your previous ones, and explore whether or not your relationships with health care team have influenced your ability to manage your long term back pain.

Should you have any inquiries, please feel free to contact me.

Thank you again for your time and participation.

Your sincerely,

Maggie Fu

Tel: 0113 343 3519

Mobile: 07809 759 652

Email: hcyf@leeds.ac.uk

Address: Room 3.35, School of Healthcare

Baines Wing, University of Leeds

Leeds

LS2 9UT



Reminder

Patient-professional partnerships and back pain self-management

Dear Mr/Ms_____:

Thank you for taking part in my study. I very much appreciate your time and effort in completing the questionnaires about your pain.

This letter is to invite you to complete the same questionnaires once more next month. Your continued participation is very important as it will enable us to compare your answers with your previous ones, and explore whether or not your relationships with health care team have influenced your ability to manage your long term back pain.

Please take a moment to fill out the attached questionnaires when they arrive and return the responses to me in the enclosed self-addressed envelope.

Should you have any inquiries, please feel free to contact me.

Thank you again for your time and participation.

Yours sincerely,

Maggie Fu

Tel: 0113 343 3519

Mobile: 07809 759 652

Email: hcyf@leeds.ac.uk

Address: Room 3.35, School of Healthcare
Baines Wing, University of Leeds
Leeds
LS2 9UT

Chair: Neil Franklin

Chief Executive: Rob Webster

Appendix viii Interview topic guide for the author



Interview Topic Guide for CI

Patient-professional partnerships and back pain self-management

The aim of this interview is to explore the influence of partnerships with health professionals, on the ability to self-manage pain. This will involve exploring:

- Experiences of partnerships with health professionals, and facilitators of and barriers to a good partnership.
- Pain self-management before and after attending SpineFit.
- Respondents' views of the influence of partnerships on their ability to self-manage pain.

1. Introduction

Aim: To introduce the research and set the context for the proceeding discussion.

- Introduce self and the University of Leeds
- Introduce the study: what it is about and who it is for (PhD research study)
- Explain how they were selected (via SpineFit pain clinic in 3 selected Health centres in Leeds)
- Talk through key points:
 - length of interview
 - interview like a discussion, although specific topics to cover
 - no right or wrong answers, their views are important
 - participation is voluntary and they have the right to withdraw at any time
 - recording of interview, with consent
- Confidentiality and anonymity, secure transfer of data, how findings will be reported
- Thank you for taking part
- Any questions they may have

STARTING RECORDING

- Confirm you have gone through information with them and they are happy to proceed

2. Personal background and circumstances

Aim: to introduce the respondent and highlight any background issues that might influence their partnerships with health professionals and their ability to self-manage back pain.

- Household circumstances (area they live in, whether live alone or with others)
- Main activity
 - whether working or not: details
 - other interests/activities
- Importance they attach to back pain and pain related issues (e.g. sleeping, mood)

3. Experiences of patient-professional partnerships

Aim: To establish experiences of partnership with health professionals; to understand facilitators of and barriers to a good partnership.

- Frequency of visiting pain clinic and length of each visit
- The number of health professionals they have seen
- Consultation and treatment process:
 - welcoming or otherwise
 - communication
 - respect
 - satisfaction, willingness to talk
 - knowledge, information, skills provided
 - involvement in treatment and care plan decision
- Views of patient-professional partnership
 - general views
 - specific opinions
 - best things about patient-professional partnership (*probe fully*)
 - worst things about patient-professional partnership (*probe fully*)
- Facilitators and barriers
 - what makes the partnership 'easier' (*start openly then probe as necessary*)

- ✓ ways to make it even better
- what makes the partnership 'harder' (*start openly then probe as necessary*)
 - ✓ suggestions to improve the partnership

4. Self-management ability

Aim: to understand how respondent self-manages long term back pain, and any changes in self-managing behaviour before and after the partnership.

Before attending SpineFit

- Knowledge and information of their back pain
- Monitoring of signs and symptoms
- Management of the pain and its impact
 - physical: e.g. exercises
 - emotional: e.g. meditation/faith
 - social life
 - cost
 - effectiveness
- Support services
 - confidence
 - access
 - ability

After attending SpineFit

- Any changes in ability to self-manage pain
 - if so, what the changes are
 - if not, how they cope with pain now

5. Influence of partnerships on self-management ability

Aim: to explore respondent's perceptions of partnerships' influence on their ability to self-manage back pain.

- Whether or not the partnership has influence on self-management ability

If yes

- Whether or not the partnership has a positive influence on self-management ability

If yes

- ✓ what the positive influences are
- ✓ how these positive influences improve your ability to manage pain
- ✓ future desired partnership and how to achieve it

If no

- ✓ What the negative influences are
- ✓ how they negatively affect your ability to manage pain
- ✓ Improvements, suggestions
 - how to improve patient-professional partnerships to achieve a better ability to self-manage pain

If no

- why not
- how would you like the partnership to influence on self-management ability


- Views on the roles of health professionals
- Any other issues they would like to raise regarding to the influence of partnerships on self-management ability

At the end of the interview:

- Thank respondent for participation in the interview.
- Check whether they have any remaining questions about the research.
- Provide reassurances about confidentiality and anonymity.
- Ask if they would like to be informed of the outcomes of the research (check how they would prefer to be informed).

Appendix ix Interview topic guide for participants



Leeds Community Healthcare 
NHS Trust



Interview Topics for Patients

Patient-professional partnerships and back pain self-management

This informal interview is about your relationships with the health care team in SpineFit, and how these influence your ability to manage your back pain.

Our conversation will be recorded with your permission. It will last for about 45 minutes and any information you give will be kept confidential and anonymous.

Our conversation will cover:

- Your background and circumstances;
- Your experiences of relationships with the health care team;
- Your views on things that help or get in the way of a good patient-professional relationship;
- How you managed your back pain before attending SpineFit;
- How you managed your back pain after attending SpineFit;
- Whether your relationships with the health care team influenced your ability to manage back pain and why;
- Your suggestions and recommendations to improve patient-professional relationships in order to manage back pain better;
- Any other questions you have about this study.

Chair: Neil Franklin

Chief Executive: Rob Webster

Appendix x Favourable ethical opinion



Health Research Authority

NRES Committee Yorkshire & The Humber - Bradford Leeds

North East REC Centre
Room 002
TEDCO Business Centre
Viking Industrial Park
Rolling Mill Road
Jarrow
NE32 3DT

Telephone: 0191 4283545

27 January 2014

Miss Yu Fu
PhD student
The University of Leeds
3.35 Baines Wing
School of Healthcare
University of Leeds
LS2 9UT

Dear Miss Fu

Study title: Exploring patients' perceptions of the nature and the influence of partnerships with health professionals on the development of self-management ability for chronic back pain.

REC reference: 13/YH/0413

Protocol number: N/A

IRAS project ID: 135538

Thank you for your letter of 20 January 2014, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered at the meeting of the Committee held on 27 January 2014. A list of the members who were present at the meeting is attached.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager, nrescommittee.yorkandhumber-bradfordleeds@nhs.net

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter	e-mail correspondence	20 January 2014
Evidence of insurance or indemnity	Henderson Insurance Brokers	19 September 2013
Interview Schedules/Topic Guides	1.0	06 November 2013
Interview Schedules/Topic Guides	Interview Topic Guide for CI Version 1.0	06 November 2013
Investigator CV	1.0	24 September 2013
Other: Supervisor CV: S. Jose Closs	1.0	24 September 2013
Other: Supervisor CV: Dr Elaine McNichol	1.0	25 September 2013
Other: Key Investigator / Collaborator CV: Mandy Young		
Other: Brief Pain Inventory (Short Form)		
Other: Research start date	1.0	28 December 2013
Other: Back pain advertisement		
Other: Reminder letter	1.0	28 December 2013
Participant Consent Form: Part 1	2.0	28 December 2013
Participant Consent Form: Part 2	2.0	28 December 2013
Participant Information Sheet	3.0	23 January 2014
Protocol	1.0	06 November 2013
Questionnaire: Hospital Anxiety and Depression Scale (HADS)		26 June 2013
Questionnaire: Partners In Health Scale		
Questionnaire: Patient Partnership in Care		
REC application		28 November 2013
Response to Request for Further Information		20 January 2014
Summary/Synopsis	1.0	06 November 2013

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

A Research Ethics Committee established by the Health Research Authority

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

13/YH/0413	Please quote this number on all correspondence
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We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely



Dr Janet Holt
Chair

Email: nrescommittee.yorkandhumber-bradfordleeds@nhs.net

“After ethical review – guidance for researchers” [SL-AR2]

Copy to: *Clare Skinner, University of Leeds*

Ms Rebecca Forster, Leeds Community Healthcare NHS Trust

Appendix xi Research management and governance approval



Leeds Community Healthcare 
NHS Trust

Telephone enquiries, please contact Linda Dobrzanska
Phone: 0113 203 3473 / 07958066828
Email: lch.research@nhs.net

Stockdale House
Headingley Business Park
Victoria Road
LS6 1PF

3rd February 2014

Miss Yu Fu
Room 3.35, Baines Wing
School of Healthcare
University of Leeds
LS2 9UT

LCH Ref: NP/0142

Dear Miss Fu

Re: Exploring patients' perceptions of the nature and the influence of partnerships with health professionals on the development of self-management ability for chronic back pain

Thank you for your recent submission to Leeds Community Healthcare NHS Trust requesting governance approval for the above study.

Following consideration of your submission I am pleased to confirm that research management and governance approval has been granted by Leeds Community Healthcare NHS Trust for the above research to take place as described in your application and accompanying documentation.

Conditions of approval

You should be aware that approval is granted subject to the conditions specified below:

- In undertaking this research you must comply with the requirements of the Research Governance Framework for Health and Social Care (2nd edition 2005) which is mandatory for all NHS employees.
- Consent for Leeds Community Healthcare NHS Trust to audit your project, which is implicit in your acceptance of approval.
- Where any amendments, substantial or non substantial are made throughout the course of the study these should be notified to Leeds Community Healthcare NHS Trust.
- A copy of the final study report should be forwarded to Leeds Community Healthcare NHS Trust.
- Should any serious adverse event(s) occur throughout the course of the study these should be notified to Leeds Community Healthcare NHS Trust using the contact details set out above.

Chair: Neil Franklin:

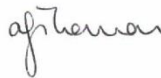
Chief Executive: Rob Webster

- You comply with Leeds Community Healthcare NHS Trust Policies on the handling of data. These policies are available from the research manager.
- You provide recruitment information upon request to Leeds Community Healthcare Research Team

Should you require any clarification regarding any of the points raised above, or have any further queries in relation to approvals and post approval study management process then please do not hesitate to contact me on 0113 2033473.

Finally, may I take this opportunity to wish you well with your study and look forward to hearing about your progress in due course.

Yours sincerely



Dr. Amanda Thomas
Executive Medical Director

Approved documents

The documents reviewed were:

<i>Document</i>	<i>Version</i>	<i>Date of Document</i>
REC Approval	13/YH/0413	27 th January 2014
R&D Form	135538/556846/14/996	-
SSI Form	135538/531013/6/194/211889/286161	-
Protocol	1	6 th November 2013
Back Pain Advertisement	-	-
Participant Information Sheet	3	23 rd January 2014
Consent Form- Part 1	2	28 th December 2013
Consent Form- Part 2	2	28 th December 2013
Reminder letter	1	28 th December 2013
Interview topic guide for CI	1	6 th November 2013
Interview topic guide for patients	1	6 th November 2013
Sponsor identified	University Of Leeds	-
Indemnity identified	Management & design Univesity Of Leeds,Conduct NHS	-

Cc:
Professor Jose Closs
Room 2.25, Baines Wing
School of Healthcare
University of Leeds,
LS2 9UT

Mandy Young
ESP Physiotherapist
Leeds Community Healthcare SpineFit team
Meanwood Health Centre
548 Meanwood Road
Leeds, LS6 4JN

Dr Elaine McNichol
Room 1.09, Baines Wing
School of Healthcare
University of Leeds,
LS2 9UT

Appendix xii Letter of access



Leeds Community Healthcare **NHS**
NHS Trust

Telephone enquiries, please contact: 0113 2033462

Email: asmith@nhs.net

Yu (Maggie) Fu
9 Oak Park Close
Leeds
LS16 6FL

Recruitment Department
Headingley Business Park
Stockdale House
Victoria Road
Leeds
LS6 1PF

31st January 2014

Dear Yu

Letter of access for research

Research Study: Exploring patients' perceptions of the nature and the influence of partnerships with health professionals on the development of self-management ability for chronic back pain

LCH Number: NP/0142

This letter confirms your right of access to conduct research through Leeds Community Healthcare NHS Trust for the purpose and on the terms and conditions set out below. This right of access commences on 10/02/2014 and ends on 30/06/2017 unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from Leeds Community Healthcare NHS Trust. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

The information supplied about your role in research at Leeds Community Healthcare NHS Trust has been reviewed and you do not require an honorary research contract with Leeds Community Healthcare NHS Trust. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.

You are considered to be a legal visitor to Leeds Community Healthcare NHS Trust premises. You are not entitled to any form of payment or access to other benefits provided by Leeds Community Healthcare NHS Trust to employees and this letter does not give rise to any other relationship between you and Leeds Community Healthcare NHS Trust, in particular that of an employee.

While undertaking research through Leeds Community Healthcare NHS Trust, you will remain accountable to your employer University of Leeds but you are required to follow the reasonable instructions of Mandy Young in Leeds Community Healthcare NHS Trust or those given on his/her behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by Leeds Community Healthcare NHS Trust in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

Chairman: Neil Franklin OBE

Chief Executive: Rob Webster

You must act in accordance with Leeds Community Healthcare NHS Trust policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with Leeds Community Healthcare NHS Trust in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on Leeds Community Healthcare NHS Trust premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf>) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that Leeds Community Healthcare NHS Trust accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of Leeds Community Healthcare NHS Trust or if you are convicted of any criminal offence. Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

Leeds Community Healthcare NHS Trust will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in Leeds Community Healthcare NHS Trust.

Yours sincerely



Terry Noon
Recruitment Assistant

Chairman: Neil Franklin OBE

Chief Executive: Rob Webster

Appendix xiii Socio-demographic and clinical characteristics collection form

Patient Information

STUDY ID

HOSPITAL

Date of Birth

Patient's Name

Last

First

Middle

Address

Postcode

Tel No.

Mobile No.

Demographic Information

Religion or Belief

Other (please specify)

Ethnic Origin

Other (please specify)

Relationship

Other (please specify)

Sexual Orientation

Screening Questionnaire

How long have you had the pain for?

Free Text

Please describe your employment

Free Text

Have you had any of the following?

Tests Investigations Scans

Please specify

Operations(surgery)

Please specify

Spinal Injections

Please specify

Physiotherapy

Please specify

Acupuncture

Please specify

Pain Team

Please specify

Alternative Treatment

Please specify

What tablets are you taking NOW for your pain?

Tablet 1

Number per day

Dose

Tablet 2

Number per day

Dose

Tablet 3

Number per day

Dose

Tablet 4

Number per day

Dose

Tablet 5

Number per day

Dose

Other

Medical History Questionnaire

- Heart Attack
- Angina
- Other heart prob
- Deep Vein Thrombosis
- High Blood Pressure
- Circulatory Problems
- Asthma
- Other Breathing Problems
- T.B
- Stroke
- Pakinson's Disease
- Multiple Sclerosis
- Diabetes
- Kidney Problems
- Hernia
- Stomach Ulcers
- Cancer
- Osteoarthritis
- Rheumatological Conditions
- Thyroid Disorders
- Osteoporosis
- Any Fractures/Broken Bones
- Joint Replacement
- Depression/Anxiety
- Any other Mental Health Prob
- Alcohol or Drug Dependency
- Epilepsy
- Vertigo
- Steroids/Anticoagulants
- Unexplained Weight Loss

- Are you a smoker?

Appendix xiv Educational background information collection form



Leeds Community Healthcare **NHS**
NHS Trust



What is your Highest Education Level?

- Degree, or Degree equivalent, and above**
 - Higher degree and postgraduate qualifications
 - Degree or degree level equivalent
- A' levels, vocational level 3 and above**
 - Other Higher Education below degree level
 - A levels, vocational level 3 and equivalent
- Other qualifications below 'A' level, vocational level 3 & level unknown**
 - Trade Apprenticeships
 - GCSE/O level grade A*-C, vocational level 2 & equivalents
 - Qualifications at level 1 or below
 - Other qualifications - level unknown
- Other Qualifications**
- No Qualifications**

Chair: Neil Franklin

Chief Executive: Rob Webster

Appendix xv Conference and seminar contributions

1. *Patient-professional partnerships and chronic back pain self-management: a qualitative systematic review and synthesis*. Poster at the 9th Congress of the European Pain Federation EFIC (September 2015). Vienna, Austria. (Accepted)
2. *Managing chronic pain: patient-practitioner partnerships and patient self-management*. Presentation at the SpotlightOn research seminars (October 2014). School of Healthcare, University of Leeds.
3. *Patient-professional partnerships and the self-management of chronic back pain*. Presentation at the 2014 Postgraduate Research Student Conference (October 2014). School of Healthcare, University of Leeds.
4. *Patient-professional partnerships and chronic back pain self-management: a qualitative systematic review and synthesis*. A poster presented at the WR DTC Psychology Summer Conference (August 2014). University of Sheffield.
5. *Applying ethical approval for studies taking place in the NHS*. Presentation at the Ethical Review Workshop (March 2014). School of Healthcare, University of Leeds.
6. *Influence of patient-professional partnerships on pain self-management*. A poster presented at the 2013 Postgraduate Research Student Conference (October 2013). School of Healthcare, University of Leeds.
7. *Patient-perceived Partnership with Health Professionals in the Development of Self-Management Ability for Chronic Back Pain*. A poster presented at 'Making the most of your Research' Conference (July 2013). Faculty of Medicine and Health, University of Leeds.